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ABSTRACT

This document contains the proceedings from the National Conference on Developmental Disabilities and Gerontology, a conference designed to develop guidelines for program development on national, state, and local levels; develop and disseminate a proceedings publication; and provide an interface between professionals working at national, state, and local levels in the areas of administration and practice. Following an introduction to the problems of the aged developmentally disabled person and a discussion of the designs and use of the conference participant's workbook, project reports are presented by representatives from five Aging/Developmental Disabilities Projects. A report on needs assessment for older developmentally disabled persons is followed by presentations of four conference workshops focusing on: (1) defining terminology; (2) examining and prioritizing service needs; (3) delineating obstacles in implementing needed services; and (4) developing models of services for the aging and aged developmentally disabled person. Issues concerning the delivery of services are discussed in presentations by representatives from four national consumer organizations for persons with developmental disabilities, e.g., autism, cerebral palsy, epilepsy, mental retardation. The materials conclude with a brief conference evaluation. The appendices contain the conference agenda, a listing of conference participants, and conference evaluation forms. (NRB)

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# CONSULTATION-CONFERENCE ON
# DEVELOPMENTAL DISABILITIES AND GERONTOLOGY

## PROCEEDINGS OF A CONFERENCE

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Ann Arbor, Michigan

May 8-10, 1978

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# CONTENTS

INTRODUCTION

The Aged Developmentally Disabled Person:
A Challenge to the Service Delivery System 5
Robert Segal

Design and Use of the Workbook 15
Wendy E. Asselin and Laura Strom

REPORTS FROM FIVE PROJECTS AND IMPLICATIONS FOR PROGRAM DEVELOPMENT

Athens, Georgia: A Perspective on Service Delivery 27
Sue T. Hartwig and Ann T. Carswell

Ann Arbor, Michigan: Programming 38
Nola Thomas

Omaha, Nebraska: Curriculum Development 62
Lee Kallstrom

Portland, Oregon: A Population Data Base 68
Constance Hanf and John Keiter

Logan Utah: Combatting Regression 93
Alan M. Hoffmeister and Michael E. Gallery

A NEEDS ASSESSMENT AND ITS IMPLICATIONS FOR SERVICE DELIVERY
John E. Gordon 107

WORKSHOP REPORTS

Workshops I and II: Defining Terminology and Prioritizing Service Needs

Workgroup 1: Paul Boodoian and John Keiter 145
Workgroup 2: Julie Meyerson and Ann Carswell 148
Workgroup 3: Edwin Butler and Shirley Bengtson 153
Workgroup 4: Ronald Stevens and Robert Ford 157
Workgroup 5: John Humphrey and Jo Hildebrand 161
Workgroup 6: Rebecca Kutz and Mary Frost 164

Workshops III and IV: Obstacles to Needed Services and Models of Service

Workgroup 1: Michael Gallery and Diane Delmas 173
Workgroup 2: Robert Day and Robert Holmes 177
Workgroup 3: Edgar Pye and Betty Hedgeman 183
Workgroup 4: Muriel Rose, Carol McKy, and Jeanie Garland 187
Workgroup 5: Irv Segal and Lee Kallstrom 191
Workgroup 6: Bob Heft and Ethel Beal 195

# CONTENTS (Cont'd)

ISSUES CONCERNING THE DELIVERY OF SERVICES FROM A NATIONAL PERSPECTIVE

The National Association for Retarded Citizens 202
John J. Pezzoli

The United Cerebral Palsy Association 213
Carol Murphy

The Epilepsy Foundation of America 227
Harold A. Benson, Jr.

National Society for Autistic Children 235
Katherine S. Stokes

CONFERENCE EVALUATION
Wendy E. Asselin 247

APPENDICES

A. Conference Agenda 255
B. Conference Participants 257
C. Evaluation Forms 266

# INTRODUCTION

# THE AGED DEVELOPMENTALLY DISABLED PERSON: A CHALLENGE TO THE SERVICE DELIVERY SYSTEM

Robert Segal, Ph.D.

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I would like to welcome each of you to this National Conference on Developmental Disabilities and Gerontology.

As you know, this conference which is being funded by the Office of Developmental Disabilities of DHEW has as its primary objectives: 1) to develop guidelines for program development on a national, state, and local level; 2) to develop and disseminate a publication in the form of a Proceedings of the Conference; and 3) to provide a long overdue interface between professionals working on a national, state, and local level in the areas of administration and practice so as to better integrate their mutual concerns and knowledge.

Because we wanted a high quality representative input from the conference attendees, attendance at the conference was to be by invitation only and to have geographic representation. We received hundreds of applications requesting permission to attend the conference. Almost all of the applicants were highly qualified. The Conference Selection Committee carefully reviewed all of the applications and selected one person from each state, including Puerto Rico and Washington, D.C. I am pleased to report that all of the states are represented here today, as is Puerto Rico and Washington, D.C. A balance of those working with all 4 developmental disabilities was attempted. However, most applicants appeared to be working in the field of mental retardation.

The format of the conference is primarily that of major presentations and workshops.

The presentations are as follows: 1) representatives from the five Aging/Developmental Disabilities Projects; 2) representatives from two governmental agencies (The Office of Developmental Disabilities, DHEW, and the President's Committee on Mental Retardation, DHEW); 3) representatives from four national consumer organizations (Epilepsy Foundation of America, National Association for Retarded Citizens, National Society for Autistic Children, and the United Cerebral Palsy Association).

There will be four workshops focusing on the following areas: 1) defining terminology; 2) examining and prioritizing service needs; 3) delineating the obstacles in implementing needed services; and 4) developing models of services for the aging and aged developmentally disabled person.

All of you were provided with workbooks to prepare you for this conference. We wanted you to begin thinking about the program implications related to data collection, defining terms, prioritizing service needs, and specifying problems related to the implementation of programs serving the aging and aged developmentally disabled person. We saw the workbook as an opportunity to develop a similar frame of reference with your colleagues attending the conference. We will try to collate the information you provided in the workbook and include it as a part of the printed Proceedings of the Conference.

Because this is the first national conference of its kind, many are looking to its outcome with keen interest. Because of your expertise, knowledge, and experience, we feel assured that your contribution will be an important one and provide guidelines to others working in the areas of gerontology and developmental disabilities.

Background

Let me review why there was a perceived need for this particular conference and what has been done with regard to the service needs of the aging and developmentally disabled person. Due to the advances in medical and health care, our elderly population is livin[illegible]onger. This also applies to deveopmentally disabled persons, that is those who have been classified as autistic, cerebral palsied, epileptic, or mentally retarded.

Because of the increasing life span of the aged developmentally disabled person there is a need to plan programs and implement services for this specific population. To do so requires a broader knowledge base for the planner and the practitioner in the fields of gerontology and handicapping conditions. Relatively little is currently known about the needs of the elderly developmentally disabled person because the focus of the program development and research efforts for the past 20 years has been in the area of early infancy, childhood or adolescence. A search of the literature regarding the older handicapped person indicates that very little has been published in this area.

In recent years, however, more attention has been focused on this group. In 1975 the Administration on Aging, HEW, funded the first National Conference on the Gerontological Aspects of Mental Retardation sponsored by the Institute for the Study of Mental Retardation and Related Disabilities and the Institute of Gerontology at the University of Michigan in Ann Arbor. As a direct outcome of that conference several states, such as Iowa, Mississippi and Virginia have implemented state wide conferences on the subject.

Another outcome of the national conference of 1975 was the support given to this important social concern by the Developmental Disabilities Office, DHEW, in 1976. The Developmental Disabilities Office recognized the need to gather data about the older developmentally disabled person and encouraged the development of training programs for personnel working with this specific population by funding five projects of national significance which focused on data collection and program development related to the needs of adult and aged developmentally disabled persons. These projects were implemented at University Affiliated Programs in Georgia, Michigan, Nebraska, Utah and Oregon and already have had an important impact on developing information about the problems and service needs of the older and aged developmentally disabled person.

## Identification of the Elderly Developmentally Disabled Client

As early as 1961, Dybwad pointed out the difficulties of obtaining data about the elderly developmentally disabled person. In 1972 I described the difficulties of trying to identify and locate this group, particularly the mentally retarded person who had been discharged from state institutions and who was living in the community. Dickerson, Hamilton, Huber and Segal (1974) highlighted the dilemma of case finding in a paper aptly titled "The Aged Mentally Retarded: The Invisible Client." Kriger (1974) described similar difficulties of client identification in her assessment study of the service needs of the aged mentally retarded person living in the community.

## Recent Survey of Service Needs

In a recent study of service needs of the substantially developmentally disabled person at the Northwestern University in Evanston and the Rehabilitation Institute of Chicago (1977) it was reported that the greatest unmet needs of this population were: (1) transportation; (2) vocational training; (3) employment; (4) financial assistance; (5) residential placement; and (6) information and referral service. While these needs relate primarily to the adult handicapped person, they become even more pressing for the elderly individual with developmental handicaps.

In another survey carried out at the Temple University Rehabilitation Center in Philadelphia (1977), it was reported that the service needs of substantially handicapped adults were in the following areas: (1) physical medicine and rehabilitation; (2) dentistry; (3) speech; (4) psychological diagnosis and evaluation; (5) counseling; (6) transportation; (7) recreational services; (8) day care services; (9) vocational services; and (10) educational services.

For those who work with the older and aging developmentally disabled client, it is clear that these gaps in services are even more severely felt by the older client.

## Additional Areas Which Need Further Attention

In addition to the previously mentioned more tangible areas of concern regarding the service needs of the older developmentally disabled person, we must add the following aspects, which while they are not often overtly expressed by the client, we must address and give recognition to: (1) the need for sexual expression; (2) the need for spiritual expression; (3) the need for personal stability; and (4) the need for opportunities to express feelings regarding death and dying.

### Sexual Expression

Developmentally disabled persons and particularly the older client are made to feel that sexuality is a superfluous part of their life. We need to recognize the meaningfulness of sexuality, even for the older developmentally disabled person, and provide them with opportunities for sexual fulfillment.

### Spiritual Expression

As life draws to a close, the older developmentally disabled person often finds the need for religious experiences and expresses a desire to become closer to God. Church affiliation and attendance at church services can provide an important sense of identity and a sense of peace for those developmentally disabled persons who have lost their sense of social belonging.

### Personal Stability

Elderly developmentally disabled persons are often forced to face separation from friends and family due to a death in the family or to ill health, which may necessitate placement in an institutional setting or a nursing home. Hitov (1975) reported on the phenomenon of "transfer trauma" which occurs when the elderly handicapped person is moved from one place of residence to another. The emotional shock created by such precipitous changes may cause a loss of identity, severe depression, regressive behavior or even death.

### Death and Dying

All human beings eventually are confronted with the prospect of death. The elderly developmentally disabled share this concern about death and dying and may need help to deal with the fears and the realities of this inevitable process. We provide assistance to the developmentally disabled with regard to their problems of living. We must be ready to assist them with their concerns about dying.

## Current Patterns in Services

To better understand the service needs of the older developmentally disabled person a survey was recently undertaken by the Aging Developmentally Disabilities Project at the University of Michigan (1978) regarding the services provided to the developmentally disabled by 41 public and private agencies in the Washtenaw County area. Ninety-four percent of the agencies surveyed stated that they served the older and aged persons. Of the persons served by these agencies, only 15% were over 55 years of age, 71% were mentally retarded, 22% were epileptic, the remainder were cerebral palsied (5%) or autistic (2%).

When the agencies did serve the older and aged developmentally disabled person, the most frequent services provided to this group of clients were: (1) information and referral services; (2) transportation; (3) ongoing counseling; (4) diagnostic assessments; (5) adult activities; (6) in home services; and (7) financial assistance.

It would appear to us that while this survey only represented a small, limited population, it is our perception that we would find similar patterns, throughout the country, indicating that most social and health agencies are not able to provide the services needed by the developmentally disabled client, and particularly those needed by the older and aging handicapped person.

## Obstacles to Implementing Needed Services

Community planners and researchers (Segal 1977, Gordon 1973) have cited factors that make program implementation extremely difficult. The following factors appear to hinder the effective utilization of existing services or impedes the implementation of needed new services: (1) difficulties involved in identifying and locating the aged developmentally disabled person; (2) lack of awareness by the consumer of the location of existing services; (3) mal-distribution of the limited, existing resources; (4) lack of trained professionals and paraprofessionals to provide services; (5) inaccessibility of services; (6) discriminatory zoning preventing the establishment of neded programs such as group homes; (7) negative community attitudes toward developmentally disabled persons; (8) lack of funding for new programs; (9) lack of inter-agency coordination; and (10) lack of community awareness of the existence of the problems and needs of the older developmentally disabled person.

## Further Inquiry is Required

At the present time little is actually known about the social, psychological, economic and medical aspects of the elderly developmentally disabled person. More research needs to be undertaken so that we can identify and locate this group and so that we can better determine their needs and develop services to help resolve their social problems.

Some questions that require further inquiry are: (1) Do the developmentally disabled tend to age more quickly than the "normal" population? (2) Does residing in the community rather than in an institution prolong life? (3) Does group home living encourage infantilization or dependency? (4) Is coordination of community services possible given the need for organizational territoriality and boundary maintenance? (5) How can the right to privacy and human decency be guaranteed to the older developmentally disabled person living in an institutionalized setting? (6) How can the developmentally disabled person best be prepared for the aging processes?

## Conclusion

In closing, I would like to thank each of you for your willingness to participate in this conference and for the contribution you will make in increasing our knowledge and understanding about the needs of the older developmentally disabled person. We look to you for your guidance and your suggestions so that we may come closer to developing models that assist in resolving the service problems of this particular group. It is our sincere hope that the ultimate outcome of this conference will be the affirmation of the right of the aging and aged developmentally disabled person to a meaningful life and a right to be provided with the needed services that foster dignity and a sense of well being.

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# DESIGN AND USE OF THE WORKBOOK

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Workbooks were distributed several weeks in advance of the consultation to prepare participants for the planning which was to occur in the workshops. The workbooks emphasized the need for active participation in this conference in order for an effective consultation to take place. Four strategies were used to achieve this objective: (1) the workbook contained some current information and literature about the aged developmentally disabled; (2) conference participants were asked to define terminology (i.e. aged, aging, developmental disabilities) and to provide information regarding what services were available for the elderly developmentally disabled person in their communities; (3) the participants were also requested to prioritize what they thought the needs of the aged developmentally disabled were and to list the programs and services necessary to meet those needs; and (4) the participants were asked to list obstacles that would prevent these services from being implemented.

The following information describes responses of twenty-eight workbooks that were completed and returned.

## Definition of Terms

In their workbooks, attempts were made by conference participants to define the following seven terms: aging, aged, developmental disabilities, autism, epilepsy, cerebral palsy, and mental retardation. In reviewing the responses in the workbook, we found that the process of defining terminology was very similar to the process utilized in the workshops. In general there was consensus on the definitions of most terms. Some participants, however, felt it important to provide variations, additions, or alternative perspectives to the generally accepted definitions. This was most true in the case of "aging" and "aged." For examples of definitions and the process involved, we refer you to the section of the Proceedings which includes the reports of Workshops I and II.

Demographic Information

Conference participants were asked to obtain information about the aged developmentally disabled who resided in their own community. First, they were asked to provide data regarding the number of aged developmentally disabled individuals as well as the total number of adult developmentally disabled in their community. The size of the former group was to be used to help determine the quantity of services needed. The size of the latter group would help determine the number of aged developmentally disabled who would be needing services in the future.

Many respondents noted the lack of available data on the numbers of aged developmentally disabled people and commented that this absence of data could prove to be a barrier to planning. It appears that many communities and states do not keep statistics concerning the number of developmentally disabled people in specific age ranges.

Community Services Available for the Older/Aged Developmentally Disabled

In order to make some determination as to the current level of services for the aged developmentally disabled, participants were asked to list the types of services available in their community specifically for the older and aged developmentally disabled and the estimated number of aging/aged developmentally disabled clients served.

Following is a list of the types of services in the order of the frequency mentioned:

1. Recreation services
2. Sheltered workshop programs
3. Day care services
4. Health related services
5. Nursing home care
6. Transportation
7. Information and referral services
8. Counselling services
9. Vocational rehabilitation and pre-vocational training programs
10. Preparation for community living programs
11. Adult foster homes; group homes
12. Homemaker services
13. Home repair and chore services
14. Advocacy and protective services
15. Institutional care
16. Respite care services

There were some difficulties in estimating the number of aging/aged developmentally disabled clients served. Some respondents could provide no information regarding client data. Some participants gave no numbers at all; several others could not differentiate between services given to aged developmentally disabled and the aged or total developmentally disabled population in general. Most participants did not state whether the numbers provided referred to annual or monthly figures. Some participants filled out this section according to state services instead of city services. The overall numbers of clients served ranged from fifteen to fifteen hundred, depending on the generality of the program.

## List of Prioritized Service Needs of the Aging/Aged Developmentally Disabled Person and Obstacles to Achieving these Services

In the third part of the workbook, the participants were asked to list in order of priority the service areas or specific programs that they felt were needed for the aged developmentally disabled person and to list any obstacles that they perceived would prevent implementing these services. Following is a list of these service/program areas and obstacles in order of the frequency mentioned:

20

| PRIORITIZED SERVICE NEED | OBSTACLES TO ACHIEVING THIS SERVICE |
|---|---|
| More appropriate residential options | Unknown client needs<br>Funding and zoning restrictions<br>Community attitudes<br>Physical barriers |
| Homemaker services | Client needs unassessed<br>Lack of funding |
| Social/recreational programs | Inadequate transportation<br>Limited funding<br>Fragmented delivery system<br>Client needs unknown<br>Untrained professionals<br>Low priority given to this area of service<br>Lack of client acceptance by general public<br>Inability to identify clients |
| Day care services | Inadequate transportation<br>Limited funding<br>Untrained professionals<br>Low priority given to this area of service<br>Inability to identify client |
| Transportation | Lack of funding (federal level)<br>Lack of state or regional transit authority |
| Adequate medical/nursing/dental care; home health care | Untrained professionals<br>Lack of funding |
| Employment training, education and placement, sheltered workshops | Fear of hiring "handicapped"<br>Employment not defined as an attainable goal<br>Lack of follow-up<br>Lack of physical space to provide employment programs |

| PRIORITIZED SERVICE NEED | OBSTACLES TO ACHIEVING THIS SERVICE |
|---|---|
| Home nutritional care (i.e. Meals on Wheels) | Lack of statistics regarding number of homebound |
| Counseling | Untrained professionals<br>Families not involved<br>Decisions made for clients<br>No coordination of counselling services |
| Information and referral | Untrained professionals<br>No coordination of community services |
| Training and education of staff, parents, volunteers, home operators | Untrained staff<br>Limited funds<br>Lack of commitment to training |
| Legal aid and protective services | Untrained professionals<br>Guardianship law needs to be redefined<br>Public/professionals are unaware of clients' rights<br>Fear of confronting the legal system |
| Respite care | Untrained professionals<br>Limited funds<br>Lack of public education<br>Zoning restrictions |
| Income maintenance | Limited funding<br>Inability to identify clients |
| Intra-agency planning and coordination: communication between boards on state and local levels | Need for coordinatred planning not recognized<br>Complexity of organizational system |

## Specific Unique Programs which might Serve as "Model" Programs

After listing the general services that are attempting to meet some of the needs of the aged developmentally disabled person in their community, participants were asked to provide information related to specific, unique programs as well as the positive and negative aspects of these programs. The following charts do not include all of the programs mentioned but illustrate a general sampling. They were selected because they have at least one of the following characteristics: the program provided a unique service for the aged developmentally disabled, it had a unique funding source, and/or it had unique benefits for the client group.

In summary, the workbook met many of its objectives. The information about the aged developmentally disabled helped to give the conference participants a common knowledge base. The workbook helped prepare the participants for the workshops by encouraging them to obtain information about the client population for which they were to develop program guidelines. The data which was compiled for the workbook served to increase the available knowledge about the aged developmentally disabled.

There were some problems with the workbook. Some participants completed none or only a few of the questions because they felt that too great a demand was being made on their time. Others felt uncomfortable or inadequate because they were unable to obtain the requested information.

The workbook succeeded in achieving one major objective: it set the stage for the consultation aspect of the experience by giving the

## SPECIFIC PROGRAMS AVAILABLE FOR THE OLDER AND AGED DEVELOPMENTALLY DISABLED PERSON

| Program Name and Address | Service Provided | Auspices | Number of Older/ Aged DD Clients Served | Positive Aspects of the Program | Problem Areas |
|---|---|---|---|---|---|
| Hope Haven School<br>950 Dearing Ext.<br>Athens, GA 30601 | Instructional program | Public | 37 | Provides choice of instructional programs to clients | May appear to be expensive at the outset, but is not |
| Community Adjustment Program Center<br>898 Georgetown Rd.<br>Lexington, KY | Adjustment program in areas of personal, social, and academic | | 26 | Works toward helping individuals acquire community services and become as independent as possible | Lack of financial aid, adequate facilities, and materials |
| Riverside Good Counsel<br>501 Farrell Dr.<br>Covington, KY 41011 | Home visits to support the DD and their families or nursing home staff | | | Works toward helping individuals acquire community services and become as independent as possible | Inadequate transportation, lack of cooperation from nursing homes |
| Peoples Community Clinic<br>408 West 23rd St.<br>Austin, TX 78767 | General medical care for elderly who cannot get help elsewhere | Public | 45 | No one refused care because of lack of money | General medical clinic at night only, no transportation for the mobily impaired after dark |

SPECIFIC PROGRAMS AVAILABLE FOR THE OLDER AND AGED DEVELOPMENTALLY DISABLED PERSON, cont'd.

| Program Name and Address | Service Provided | Auspices | Number of Older/Aged DD Clients Served | Positive Aspects of the Program | Problem Areas |
|---|---|---|---|---|---|
| Relaxation/Body Movement Program<br>Travis State School<br>430 Webberville Rd.<br>Austin, TX 78767 | Teaches clients how to relax, to identify body parts, to learn to interact with peers in a group | Public | 12 | | Lack of space for other similar programs |
| Madison Area Retarded Citizens<br>501 Badger Rd.<br>Madison, WI 53715 | Day services | Public | 20 | Social skills, work habits | Not enough room |
| Family Placement Program<br>Dept. of Health and Rehabilitative Services<br>Retardation Program Office<br>1311 Winewood Blvd.<br>Tallahassee, FL 32301 | Caretaker services, any service/program necessary to remove barriers | Public | 60 | Allows person to remain at home/family and avoid institutionalization | Legislative restraints, budget |

SPECIFIC PROGRAMS AVAILABLE FOR THE OLDER AND AGED DEVELOPMENTALLY DISABLED PERSON, cont'd.

| Program Name and Address | Service Provided | Auspices | Number of Older/ Aged DD Clients Served | Positive Aspects of the Program | Problem Areas |
|---|---|---|---|---|---|
| Alhambra Recreation for the Handicapped<br>3800 Grand Ave.<br>Phoenix, AZ 85019 | Recreational programs | Private | 215 | A place for handicapped to meet, have recreation, and learn new skills | Little funding |
| Project Restore<br>Cass Methodist Church<br>23 E. Adams<br>Detroit, MI 48202 | Avocational training | Private | 25 | Socialization programs life enrichment, occupational therapy; geographically distributed, serves over age 50 | Inadequate control over long term home placement, long waiting list, transportation |
| Fort Ruger Center<br>2989 Diamond Head<br>Honolulu, HI 96816 | Craft skills, recreation, multicultural education | Private | 30 | Incorporates ethnic traditions in a stimulating activity program, mean age of clients is 50-62 | No one older than 62 served now |
| Adams-Wells Training Center<br>RR #3, Box 213-A<br>Bluffton, IN 46714 | Inservice training for nursing home personnel | Private | 30 | Assists nursing home staff in working more appropriately with mentally retarded clientele | |

participants responsibility for a direct contribution right from the start. As a result there was a feeling of early involvement which contributed to the general success of the conference.

# REPORTS FROM
# FIVE AGING/AGED DEVELOPMENTAL DISABILITIES PROJECTS
# AND IMPLICATIONS FOR PROGRAM DEVELOPMENT

# A PERSPECTIVE ON SERVICE DELIVERY TO AGED DEVELOPMENTALLY DISABLED ADULTS

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The researcher must possess a true pioneer spirit to accurately pinpoint aged developmentally disabled adults. The basic questions of "how many" and "where they are" inevitably result in frustration and disappointment. Perhaps the most common obstacle in the identification process is the lack of familiarity with the term "developmental disabilities." The term is of recent origin and is not in widespread usage. Service agencies not within the developmental disabilities disciplines use other criteria for their particular service eligibility, and the existence of a developmental disability may not be readily identifiable in the case of an individual client.

Client confidentiality is a difficult legal question, and the fear of violating this confidentiality may hamper investigation in some instances. The same type of fear is reflected when utilizing lay persons in a grass roots approach to identification. Due to possible negative connotations involved, persons will often be willing to give demographic information but not the names of clients. This fact may be attributed to the fear of "embarrassing" the developmentally disabled or their families or violating the clients' legal rights.

The developmental disabilities discipline itself has traditionally directed its attention to the young. Many older developmentally disabled adults are not known to vocational and educational services, and due to lack of follow-up, there is little or no current information on those who were served in the past. The available data concerning older developmentally disabled persons tend to be lumped in the one category of "adult." It is generally not broken down into age groupings.

The older the age group being studied, the greater the difficulties in adhering to the present federal guidelines of the developmental disabilities definition. Diagnoses and conditions become masked throughout the life span due to a variety of circumstances. It is often difficult to validate a condition which occurred during a developmental period dating 30, 40, 50 or more years ago.

Early medical data and other indicators commonly used to denote trends are not generally available for the elderly population. Earlier primary disabling diagnoses may be superceded to reflect more recent impairments. At times, the masking of a developmental disability may be deliberate for a variety of pragmatic reasons. Service programs traditionally center on specified populations and, to gain a prospective client access to services, a case history may be slanted for eligibility. For example, the acknowledgement of mental retardation may complicate an individual's eligibility for a specific program service and may, therefore, not be mentioned in the client's case history.

Almost all of the reports regarding the aged developmentally disabled population issued to date speak of the need for additional research. To focus attention on a specific group, it is common to quote facts and figures. It is the traditional method--the classical approach.

Aged developmentally disabled persons comprise only a small percentage of the entire general population. The same factors increasing the numbers of aged persons in general should also increase the numbers of aged developmentally disabled persons. A compensating factor for the significant increase of projected figures is that succeeding generations of developmentally disabled adults should require less attention. The view is based on two premises. The first is that biomedical prevention will achieve greater success in the reduction of incidence, and the second is that progress will be achieved in communitization. (The term communitization refers not only to community support services in the deinstitutional process but also to institutional avoidance.)

The report prepared by the President's Committee on Mental Retardation in 1976 maintains that "if we applied all we know, we could reduce the incidence and social impact of mental retardation by at least half. If we continue to develop knowledge and apply it to the problem at the rate of the past 25 years, mental retardation can be brought under effective control by the end of this century!"

Many reports concerning the aged developmentally disabled stress the need for further data collection. To reiterate, this is traditional to secure attention. An abundance of information is readily available, but greater efforts should be made to consolidate and disseminate existing information. Rather than concentrate future efforts on refining percentages, focus should be on methods of meeting the needs of aged developmentally disabled adults.

Aged developmentally disabled adults are not receiving social services to an effective degree. This is not a singular case of discrimination. Unmet needs are a characteristic common to all impaired populations. Literature abounds with listings of needs and the corresponding gaps in service delivery.

Service needs are complexly interrelated. Impaired functioning in one area influences performance in other areas. For example, an individual's physical impairment effects his mental health, financial and social resources, and daily living skills. It is difficult to prioritize service needs without invoking considerable discussion and debate. However, almost every impaired population publishes its list of priority service needs.

In order to meet the variety of needs, careful service delivery planning is a necessary and difficult task. A continuum of residential and support services is necessary to enable impaired adults to remain in the community. It became obvious that community support systems were not satisfactorily developed when the big push to deinstitutionalize began some fifteen years ago. Extensive community support systems are possible; however the cost effectiveness factor can not be ignored. Finances seemingly dictate that every need of every individual cannot be met.

A most unwieldly factor in service delivery planning is the lack of homogeneity within an impaired population. The aged developmentally disabled population is not a homogeneous group nor is it static; the frail elderly population is not a homogeneous group, nor is it static. Each member of a population possesses his own unique functioning levels. It is indeed difficult to offer a range of integrated services to achieve community residency.

The service needs of aged developmentally disabled adults and the frail elderly are not dissimilar. At any point during the life span, the difference in service needs for developmentally disabled persons and the population in general is one of degree of service. Developmentally disabled persons require the same developmental and supportive services as other programs. Modifications or adaptations of the services may be required or desired at times, especially in terms of education and training. The need for modification diminishes as an older person's needs shift from developmental services to supportive services. For these reasons, developmentally disabled persons should be served through regular service systems. Because of negative stereotypes concerning developmentally disabled persons, monitoring of service programs may be desirable to prevent discriminatory practices.

For more effective delivery of all social service systems, thought should be given to streamlining processes. Many times, due to excessive red tape, the actual delivery of a needed service suffers. Extensive codification of rules and regulations to specify a standard service in increasing detail greatly reduces flexibility in meeting individual needs. Under this organizational structure, programs have little opportunity to change in response to needs, and needs tend to express themselves in terms of what services are available. Greater flexibility and attention to individual need should have a positive impact on service delivery systems.

Another important factor in establishing more effective service delivery is coordination of various service programs. No one agency can hope to provide the array of differentiated services needed by an individual. Often there is voluntary cooperation between agencies, but without the development of a policy which outlines responsibilities, coordination can be lost as contact persons change jobs and are replaced. Coordination of services should be a matter of policy rather than personal inclination. Multi-purpose service centers, already in existence in some rural areas, might be an effective means of implementing an integrated service system.

Social services traditionally focus on the recipient directly, with little thought to the roles of other persons who are closely involved. The majority of the elderly live with a spouse or other family member. There is a growing consensus among gerontologists that the key to preventing or delaying institutionalization of the frail elderly lies with the role of the caretaker. This same concept is being embraced by many in the developmental disabilities disciplines. More and more attention is being given as to how the caretaker's burden may be relieved. Nevertheless, with the degree of community support services that are currently available, the choice, in most instances, remains "no care" or "total care" for the impaired family member.

The importance of the caretaker's role should never be understated. Observations have been made that the caretaker is the all encompassing support of a severely impaired person. Additionally, studies have shown that persons with the same degrees of impairment as those institutionalized remain in the community.

A good nursing home provides more than twenty types of services. All these services can be duplicated for the community resident. However, the cost of the parade of workers and programs that would be involved renders the concept infeasible. Logic would seem to dictate that the role of the caretaker becomes a focus. Support services to ease the burden of the caretaker of the impaired adult would include home-health and homemaker aid services, adult day programs for the impaired, companion services, etc. Some are suggesting that a cash supplement paid to the caretaker to ease the financial burden might prove to be an effective incentive for home residency of the impaired adult. There will always be a need for institutional care for the more impaired individual, but that care should be reserved for those whose needs dictate such a placement. An institution may be the most appropriate setting for persons whose needs require complex 24-hour a day services. The provision of support services to the caretaker would help insure feasible home residencies and appropriate institutional placement.

If community residency for developmentally disabled adults is to be a viable alternative to institutionalization, training programs will have to be a part of the service system. A prime need of elderly developmentally disabled and their caretakers is a readily available information and referral service, with counseling for those who need it. In-service training programs for personnel working with the aged and aging developmentally disabled should concentrate on this need. Services are so often fragmented that recipients are lost as to where to begin, and just as often service personnel focus on the disabilities rather than the needs, thus passing over existing services as a resource for the developmentally disabled and their caretakers. Service personnel would benefit from instruction and training in using existing services to meet the needs of the developmentally disabled, with emphasis on a coordinated range of services.

Inservice training for home-aid personnel, as well as caretakers, should include self-help skill techniques to foster independence of the impaired individual. This might necessitate additional equipment or apparatus for the home, but would hopefully enable the caretakers to serve the needs of the disabled without regular outside systematized assistance and enable the developmentally disabled to function as independently as possible. Instruction to the impaired individual in the performance of activities of daily living and social skills should be included in suitable training programs to further promote independence of the recipient.

Personnel in-service instruction and training should focus primarily on those engaged in direct service, regardless of whether that service is community or institutionally based. Inherent in each program whould be sensitivity training to help dispel generalized preconceived notions and the tendency to label and stereotype. Emphasis on the individual--his abilities, resources and needs--will help assure appropriate service delivery.

If the communitization concept is to be used successfully within the service delivery system, some effort, will have to be directed toward increasing the level of community awareness and acceptance of developmentally disabled persons. Service practices relate clear messages about the systems' values, and many practices such as unnecessary segregation and inappropriate age activities support negative public attitudes toward developmentally disabled persons. As previously stated, developmentally disabled persons are not a homogeneous group, and stress should be placed on their varying individual needs and abilities rather than the label they share. Services structured to enhance the common humanity and individuality of "disabled" people would go a long way toward a more positive public attitude. Recognizing that every human community has a complex and often contradictory value structure, adopting service methods which appeal to positive community values is more appropriate than assuming the community will be nonaccepting and intolerant.

The person with a developmental disability has historically been seen and treated as if he were less than human, a menace to others, a sick or diseased organism, an object of pity and charity, an eternal child. It is human nature to be wary of the unfamiliar. Efforts at communitization with physical and social integration will help provide person-to-person interactions. Learning about persons with developmental disabilities through social exposure and the opportunity to get to know them in typical community settings will influence stereotyped attitudes in a positive manner.

The media can play a part in this "getting to know" process. An example: the PBS children's series "Feeling Free" was funded as a means of introducing youngsters to their disabled peers. The "regulars" on the show are disabled youngsters who engage in games, hobbies and rap sessions with their non-handicapped guests. The message is loud and clear--disabled children behave like ordinary kids. To answer queries about what it is like to be disabled grown-up, there are three mini-documentaries about disabled adults.

Advocacy, usually on behalf of individuals or classes of people in order to obtain appropriate services, should also include efforts toward increasing public awareness and acceptance of developmentally disabled persons. One method would be conducting community workshops for public education. Special workshops could be held for specific groups such as law officials and educators. With the knowledge of key individuals and agencies administering the resources, advocates can influence the formal and informal mechanisms which are required to insure success in promoting communitization.

The issues raised and solutions proposed in this report are by no means innovative, nor do they guarantee a workable solution to meeting all the needs of the elderly developmentally disabled. The term "develop innovative service models" needs careful interpretation. It is a most popular ending to reports concerned with populations needing social services. But, it tends to imply that if studies continue long enough a magical solution will evolve. There is a vast store of knowledge at hand. Excellent social services are already in existence; however, the programs are fragmented in isolated areas throughout the nation. It may well be that the emphasis should be on geographical expansion and eligibility modifications of existing service models rather than the continual search for new ones. By applying what we already know through existing services we can be on the lookout for additional problems and their solutions.

In summary, a spectrum of integrated community and caretaker support services are necessary to prevent and/or delay institutionalization. The needs of aged developmentally disabled adults are not dissimilar to those of the frail elderly and those of young and middle aged developmentally disabled adults. Aged developmentally disabled adults are few in number and are dispersed throughout the general population. Additionally, they are not a homogeneous group and represent many varied service needs. In view of these factors, cost effectiveness in all likelihood prohibits the establishment of a delivery system of social services solely for their benefit. Aged developmentally disabled adults can be and should be served by regular social services. However, care will have to be taken that the developmental disability label does not prevent access to services for the elderly and that the age factor does not prevent participation in appropriate programs for young and middle-aged developmentally disabled adults. Like many concerned with the welfare of elderly and developmentally disabled persons, we would like to see an array of services in every community. But with financial limitations and the need to systematize services, perhaps the most realistic, effective approach to meetwng needs would be a base of core services for a broadly defined group rather than a complex system of specific services for just a few.

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# PROGRAMMING FOR OLDER AND AGED DEVELOPMENTALLY DISABLED ADULTS

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## Introduction

Modern medical knowledge and technology has decreased the mortality rate at all ages so that more people are living longer. This statement is also believed to hold true for developmentally disabled persons. While in previous years, many developmentally disabled people would have succumbed to their medical problems, today there are indications that many are living well beyond their adolescence. Demographers in gerontology have pointed out that the post war (1945-1957) "baby boom" has led to increasing numbers of aged persons in the society. These numbers are expected to increase significantly--as much as 30% within the next twenty-five years (Siegal, 1976). It is expected that a substantial proportion of this aged population is now and will be developmentally disabled. This hypothesis is the rationale for five projects on aging and developmental disabilities funded by the Developmental Disabilities Office (DHEW) at University Affiliated Programs in the states of Utah, Georgia, Oregon, Nebraska, and Michigan.

## The Michigan Project - Overview

Like the other four projects, the Michigan project is primarily concerned with increasing data, knowledge, and expertise about the aging and aged developmentally disabled population. These areas represent a broad spectrum of need; there are still many unanswered questions, and each project has operationally defined its own method of implementing this long-range goal.

In Michigan, the Aging/Developmental Disabilities Project is working toward this goal through the following integrated series of activities: (1) collection, organization and interpretation of data; (2) identification, development, and implementation of demonstration model programs; (3) development and implementation of training programs; (4) provision of technical assistance and consultation; (5) development of training materials; (6) dissemination of information and materials; (7) formation of a constituency of interested persons and organizations; and (8) formation of a working Consortium with the other five Aging/Developmental Disabilities Projects. Figure 1 provides an overview of Project objectives.

This paper will describe the project's data collection activities; and its implementation of demonstration programs in 1) body movement; 2) group counseling; and 3) clinical assessment and advocacy. Other project training materials such as a definition paper on the aging and aged developmentally disabled population, a video-tape on the dental care needs of this group, and videotapes on the aged mentally retarded are available as instructional aids but will not be discussed here.

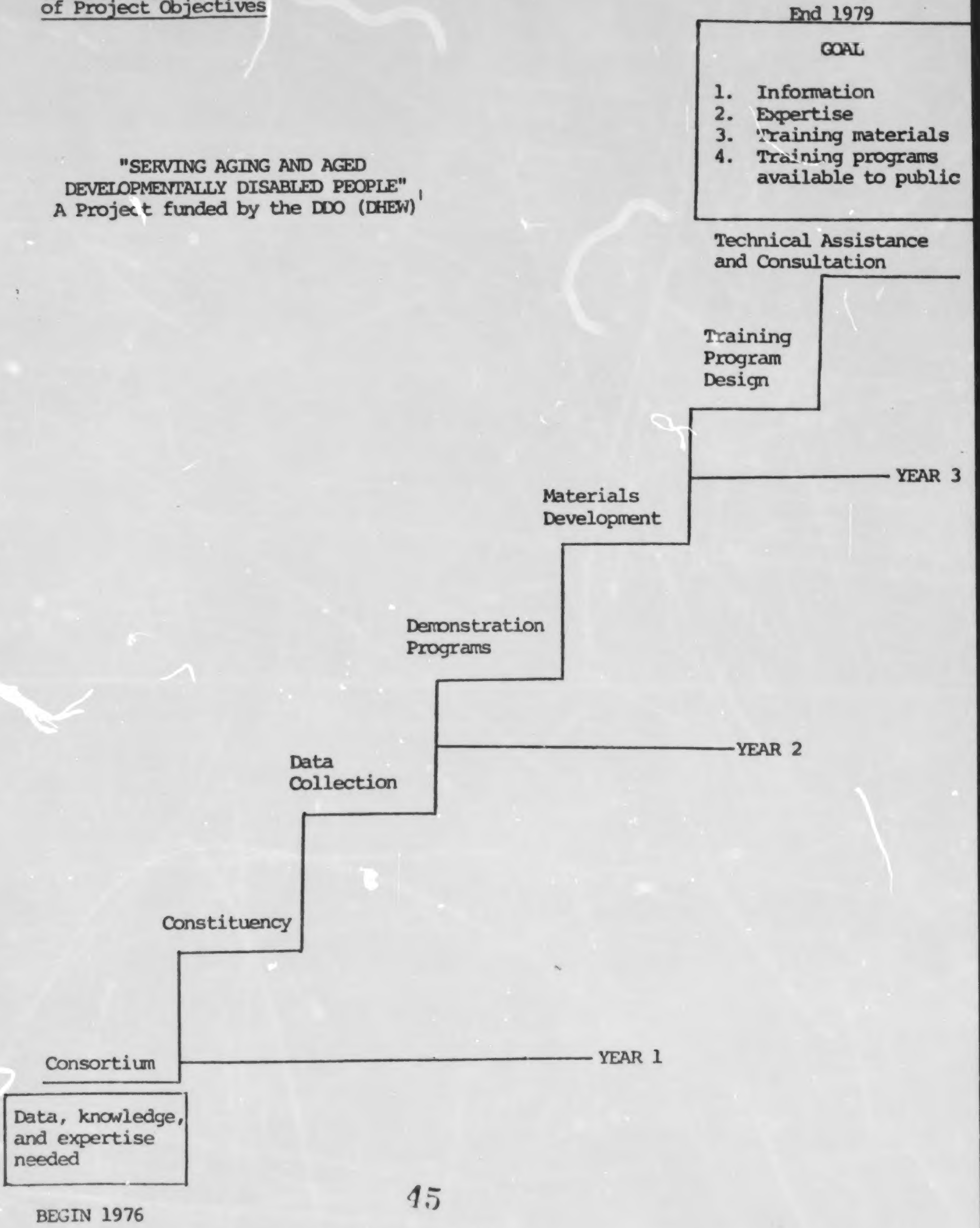
## Data Collection Activities

The project is collecting, organizing, and disseminating data on the aging and aged developmentally disabled population. The data are to provide an information base for planners and decision-makers responsible for program development. Data are considered to be any type of factual information or materials which can be used as a basis for reasoning or decision-making.

FIGURE I.

Chronological Overview
of Project Objectives

"SERVING AGING AND AGED
DEVELOPMENTALLY DISABLED PEOPLE"
A Project funded by the DDO (DHEW)


End 1979
GOAL
1. Information
2. Expertise
3. Training materials
4. Training programs available to public
Technical Assistance and Consultation
Training Program Design
YEAR 3
Materials Development
Demonstration Programs
YEAR 2
Data Collection
Constituency
Consortium
YEAR 1
Data, knowledge, and expertise needed
BEGIN 1976

While it is apparent that many generic services to this population do exist (e.g. Social Security, Public Health Services, Welfare Services, etc.), the type, number and impact of these and other, specialized, services is not readily available information. There is a need for this kind of information which can be used to make decisions regarding allocation of resources and program planning for aging and aged developmentally disabled people.

Because the Developmental Disabilities Office, other federal agencies, and some federally funded projects are currently in the process of collecting demographic data, [illegible] Michigan project decided to focus its data collection activities on the assessment of community services provided to aging/aged developmentally disabled people in selected areas of HEW Region V (Michigan, Wisconsin, Minnesota, Illinois, Indiana, and Ohio). It is expected that the results of this limited survey will have implications for service delivery nationwide.

The mail survey consisted of a questionnaire which was developed to do the following: (a) determine how many older/aged developmentally disabled persons are receiving services from each public and private agency selected; (b) identify existing services available to this population; (c) determine the need for additional services for the older/aged developmentally disabled population; and (d) identify obstacles/barriers to effect service delivery. Because of the utility/feasibility of data collection at the service delivery level, it was further decided that the study would initially be restricted to the state of Michigan. In order to evaluate a pilot instrument, a questionnaire was distributed to local agencies in Washtenaw County serving this client group. The pilot instrument specifically focused on the following kinds of information: (1) the age range of developmentally disabled persons served by an agency; (2) the number of clients served in the older and aged categories; (3) the types of developmental disabilities present in the agency's target populations; (4) the range of services provided to older developmentally disabled clients; (5) the frequency with which services were rendered to older developmentally disabled clients; (6) the identification of specific services provided to older developmentally disabled clients; (7) the identification of older developmentally disabled clients known to not be receiving services; (8) the identification of sources of program funding; and (9) the identification of perceived barriers in provision of service to older developmentally disabled clients. The information obtained from each of the questions can be cross-tabulated so that inferences from the raw data can be obtained.

## Results of Pilot Study

The original questionnaire was sent to only those agencies providing direct services to developmentally disabled clients in Washtenaw County and to a limited number of randomly selected locations out-of-state. If an agency did not provide services to the target population, or if it was not able to "differentiate" this population from other clients, no questionnaire was sent. In Washtenaw County, this was determined by a phone call. Agencies included were: local state offices of Social Services, Public Health, Mental Health, Mental Retardation, Vocational Rehabilitation, and other related private/non-profit agencies. Services to the aged, nursing homes, public educational and recreational programs were also surveyed if they served developmentally disabled clients. Out-of-state agencies were identified by their requests for information from the aging project.

A total of 41 questionnaires were mailed; 36 were returned; 34 were usable; 8 were from out-of-state. This was a response rate of 85%. While the sample was not sufficiently large enough to be analyzed using inferential statistics, descriptive statistics have helped to refine the questionnaire and have revealed some interesting trends in the responses received (see Table I).

For example, 94% of the respondents indicated that they are serving older/aged developmentally disabled clients. Those respondents who reported clients served by age indicated that 85% of those served were in the 35-54 age range with only 5% of those served falling in the over 65 category. As expected, mental retardation was listed most frequently (71%) as the primary diagnosis of clients served, followed by epilepsy (23%). However, the figure for epilepsy is felt to be high as one of the agencies surveyed, The Epilepsy Foundation, compiles data for the entire state, whereas the other agencies surveyed maintain records primarily at the local or county level.

The pilot also indicated that information/referral services (88%) and transportation (75%) were the two services most frequently provided. Legal services, dental treatment, guardianship and vocational classes were the services provided least frequently.

Further, 22% of the respondents reported having identified 100 older/aged developmentally disabled clients in need of service but not presently being served. However, that figure does not present an accurate picture as agencies may be reporting the same clients. Of those agencies responding, 78% indicated that they received some federal support and 74% indicated that they received some state support.

TABLE I

## Preliminary Review of Pilot Survey Results

N = 34 41 Forms Mailed 34 Returned 8 Out-of-State

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1. The response rate of 83 % is very good for a mail survey.
2. 94% of respondents are serving older/aged DD clients.
3. Those respondents who reported clients by age indicated:

   64.7% served ages 35 - 54
   44.1% served ages 55 - 65
   44.1% served ages 65+

4. Those respondents who reported by clients' disability are indicated:

   23% - Epilepsy
   5% - Cerebral Palsy
   2% - Autism
   72% - Mental Retardation

5. The five services offered most frequently by agencies were:

   1) Information/Referral - 88%
   2) Transportation - 75%
   3) Ongoing Counseling/Treatment - 66%
   4) Diagnostic Assessments - 44%
   5) Adult Activities/Recreation - 41%
   Funding - 41%

6. The four services offered least frequently by agencies were:

   1) Legal Services - 0%
   2) Dental Treatment - 16%
   3) Guardianship - 19%
   4) Vocational Classes - 25%

7. 32% of the agencies reported a total of 185 clients identified as needing service but not receiving it.

TABLE I (Continued)

8. a) 75% of the respondents reported receiving federal funds
   b) 82% of the respondents reported receiving state funds
   c) 47% of the respondents reported receiving county funds
   d) 29% of the respondents reported receiving private funds
   e) 16% of the respondents reported receiving special grants

9. Respondents reported the three major problems in providing services to older/aged DD clients were:

   1) Inadequate Funds - 66%
   2) Lack of Community Supportive Services - 66%
   3) Transportation - 63%

10. Most of the surveys were completed by social workers.

11. An example of cross-tabulation possibilities is that of those agencies providing adult activity recreation:

    A. 26.47% received Federal funds
    B. 32.35% received State funds
    C. 37% received County funds

Finally, respondents listed inadequate funds (70%), lack of community support services (61%) and transportation (61%) as the major problems faced in providing services to older/aged developmentally disabled clients.

Based on the results of the pilot survey, the project has elected to proceed with a sample survey of services to older/aging developmentally disabled clients within Region V. The questionnaire was revised as suggested by the pilot. Two counties in each state in Region V will be sampled. The counties will include one principal urban center in each state and a selected university center. It is believed that services to older/aged developmentally disabled clients are likely to be over-represented in these areas, therefore if service gaps are identified there, it can be assumed that larger gaps probably exist across the entire region in other, more rural areas.

In addition to agencies typically serving developmentally disabled clients, the revised questionnaire will be sent to all agencies providing services which could, and should, be available to developmentally disabled clients. This action is intended to convey information to agencies regarding developmental disabilities and Sec. 504 of the Rehabilitation Act of 1973 which calls for "barrier-free" access to all federally funded programs. It was also determined that a modification of the questionnaire focusing on student personnel training would be developed to send to University Affiliated Programs (UAP's).

## A Need for Programs

Although present demographic data is inconclusive regarding the actual number of aging and aged persons in this country, there is evidence that perhaps as many as half of all developmentally disabled persons are over age twenty-one. It is apparent, even without the specific data, that people live out the greatest portion of their life span as adults. The periods of infancy, childhood, and adolescence comprise little more than the first quarter of the average life span. The remaining three quarters of a person's life span, between the ages of twenty-one and approximately seventy, are spent as adults--young adults, older adults, and aged adults. A wide array of diversified programs should be designed to meet the needs of developmentally disabled persons as they progress through adulthood.

It is not enough for a developmentally disabled person to receive special education to move on to semi-independent community living without further concern as to the kinds of help he needs to live out the remainder of his life with more meaning. As developmentally disabled people age biologically, that is begin to decline in physical capacity, emotional and psychological development does not necessarily also decline. Rather, as is being discovered with the non-disabled elderly population, there is ongoing development in these areas throughout the life cycle. This development is also possible for developmentally disabled persons if they are given opportunities to develop new skills, to acquire new friendships, to learn and understand new things.

Programming in day treatment and residential facilities can become more effective and innovative in creating a stimulating, growth producing environment. The demonstration programs carried out by the project and described below were designed to stimulate the use of therapeutic activities with aging and aged developmentally disabed persons and to gain insight into the service and other needs of this population.

The information obtained from the demonstration programs will be compiled into training manuals or guidelines for agencies.

## Therapeutic Arts/Inservice Workshops

The project attempted to create an innovative inservice instructional model by conducting short-term demonstration programs in the areas of: (1) body movement; (2) music; (3) art; and (4) poetry therapy.

The programs were designed to stimulate client, staff and agency interest and involvement in art form therapies in addition to broadening staff awareness and understanding of aging/aged developmentally disabled persons. The programs gave the practitioner familiarity with the particular art form employed and equipped him or her with skills to use the art form to enhance daily program activities for clients. It was also expected that the programs would collect new data on aging and developmental disability and raise questions for further research.

Self-expression, like freedom of motion, can be restricted in old age because of inactivity, and physical and emotional incapacity associated with aging. The aging or aged developmentally disabled may experience feelings of insecurity and fear due to age-related disabilities in physical appearance or social status. Isolation and depression in old age may inhibit a client's expression of feeling. He or she may cease to be creatively involved with life. Participation in art form activities helps the older and aged developmentally disabled person find new possibilities for expression and communication, and thus contributes to his or her basic sense of well-being and self-worth.

The programs or workshops, lasting six to ten weeks, were carried out with small groups (six to twenty persons) of older and aged developmentally disabled adults and agency staff in a group home, a nursing home, and an adult activity center. They were designed to provide: (1) an economically feasible inservice training experience for staff, and (2) an educational and therapeutic experience for clients.

The therapeutic use of art forms had been employed in the treatment of children and psychiatric patients. It was also becoming more popular in programming for the non-disabled elderly. However, it had not typically been used to train both staff and clients in developmental disabilities settings.

The model calls for 1) peer-like participation of staff and clients in an art form experience followed by 2) staff-therapist discussion facilitated by a project group leader. During the therapeutic session, both staff and clients followed the instructions of the art form therapist. They worked on similar tasks together. This experiential approach was based on the principal that education is a growth process which demands direct learner participation and involvement rather than passive observation or acceptance of information. The use of therapeutic art forms expanded beyond traditional inservice practices by exploring alternative strategies to learning. The joint participation of staff and clients was based on the belief that their relationship was a critical factor in the teaching-learning process which went on between them, not only in the Workshop but in other aspects of the agency's programs.

The workshops endeavored to mitigate the negative effects of aging and build on its positive aspects. They tried to expand the possibilities for non-verbal expression and communication, and hence, provide an opportunity for enhancing assertiveness and self-esteem. The art activity was a method for stimulating (1) sensory and motor functioning, (2) cognitive awareness, and (3) new social behaviors. All the workshops attempted to develop the clients' capacities (1) to identify emotions and to express them though an artistic medium; (2) to follow oral directions; (3) to develop concentration and attention span; (4) to develop patience and perseverance; (5) to develop assertive characteristics; (6) to learn to interact with peers in a group situation; and (7) to develop an awareness of the various ways art forms can enter into daily living activities.

Fundamental to diagnosis and treatment are the abilities to identify and categorize client needs, to understand the dynamics of client behavior, and potential for change. The workshops helped staff to understand the process of singling out and interpreting behavioral cues as they explored the art form with their clients. Through peer-like participation in the therapeutic art experience, staff gained insight into their own feelings and behavior and that of clients. Their direct involvement in the process provided an opportunity for first-hand awareness of what the tasks involved, both physically and emotionally. This personal experience coupled with the opportunity to see clients in an atypical situation, provided important diagnostic and treatment information.

Following the hour-long therapeutic art form session, agency staff and the art therapist met for another hour with a discussion leader who had also participated in the experience. The purpose of the meeting was to discuss what occurred during the session, what responses it generated in staff, and how it affected the clients individually and as a group. It was also a time to clarify and discuss teaching approaches used by the therapist.

Although the therapeutic art forms inservice workshops were exploratory ventures which still need refinement, the evaluative responses of staff and clients indicated that the experiences were worthwhile and potentially useful in expanding their regular programming. Clients enjoyed participating in the sessions and staff reported new insights into client behavior. The use of art form therapies holds promise for introducing unique and varied programs into day and residential activity programs.

### Group Counseling

In addition to the therapeutic arts inservice workshops, a demonstration counseling group was carried out with older and aged developmentally disabled clients. The program was designed to: (1) enhance and deepen the group workers' knowledge about counseling this population; and (2) to demonstrate the personal development potential of developmentally disabled older adults which may occur as a result of a group counseling experience.

As retarded and developmentally disabled persons begin to age and become aged, they encounter life experiences similar to those of their non-retarded, non-disabled peers. They must develop an emotional understanding of their purpose and place in life--whether or not that purpose can be expressed verbally. It was expected that this would involve resolving a number of conflicts, fears, and frustrations, most notably dealing with the issues of the retardation or disability itself, marriage and children, personal freedom, work, poverty, illness, and death. In addition, many older and aged developmentally disabled adults reach the later phases of the life cycle with the additional burdens of a previous lengthy institutionalization and life long infantilization. These experiences increase the likelihood of sustained emotional and interpersonal difficulties which interfere with the individual's progress in adjusting to community living and with his or her sense of well-being. Together with other unique emotional adjustments of the developmentally disabled person's adult life, these difficulties could lead to his or her institutionalization or reinstitutionalization.

It has been said that older adults in general face the developmental task of redefining their social identity. Older developmentally disabled adults also face this task--usually at an earlier age. It has also been pointed out that "persons with retardation have the same psychological needs as any other human beings" (Browning, p. 246, 1974). Sensitivity to these needs and to the developmental tasks of developmentally disabled adults can develop from observing their manifestations in the group process.

The group was jointly carried out by two social workers; one from the Aging/Developmental Disabilities Project, the other from the host agency. It was small, consisting originally of six people and two staff, and lasted ten weeks. Clients were selected on the basis of age (the youngest was thirty-seven years old), verbal abilities, and similarity of background and experience. Clients with severe psychotic behavior were excluded.

Because of the program's short duration, marked changes in client behavior were not expected. The major goals for the group were: (1) to increase verbal interaction among members; (2) to increase members' ability to see choices and make decisions; (3) to increase client's ability to recognize, label, and express feelings; and (4) to enable members to identify socially appropriate behavior for the expression of feelings. Individual client goals were established following a procedure which involved: (1) the agency's suggestion of possible candidates for the group according to the specified criteria; and (2) interviewing of each client by the group leaders regarding his interest in group participation, confidentiality, expectations regarding attendance, the purpose of the group, and his individual concerns. Client goals were divided into two types: behavioral goals and personality change goals. The behavioral goals were to be specific, observable changes in behavior. Personality goals consisted of long-range interpsychic changes that involved intangibles such as strengthening of ego functioning, improving self-image, increasing feelings of acceptance and hope. The goals identified for clients at the beginning of the sessions changed as the group process uncovered other individual concerns. As Schopler and Galinsky (1974) point out, "Goal formulation is a process, not an event; goals are constantly evaluated and re-evaluated."

Movement toward the accomplishment of the goals was evaluated subjectively at the close of each session and at the end of the counseling experience by the group workers. No attempts were made to systematically analyze or examine the behavioral change of clients toward the identified goals.

The most significant outcome of the group counseling sessions was the identification of themes or areas of concern common to many aging and aged developmentally disabled adults. The themes significantly paralleled those issues which staff expected would be problematic to this age group. They were: (1) restrictiveness of the living situation and problems in living with others; (2) money handling, wanting things, poverty; (3) understanding how non-developmentally disabled persons function and accepting oneself as a person with a developmental disability; (4) understanding the effect of one's disability on others; (5) acceptance of infantilizing roles; (6) expression and control of strong emotions; (7) being sexual; (8) living with an ill, aged parent and death of aged parent(s); (9) problems in transportation and mobility; (10) plans for the future, marriage, and intimate relationships; (11) interactions with other clients who have inappropriate behavior; (12) restrictiveness of the day activity program and belonging to a subculture within the program; (13) aloneness; and (14) growing old and looking old versus wanting to be young, thin, and gorgeous/handsome and strong.

Although group counseling and psychotherapy is known to be effective in assisting persons to develop and mature emotionally, it has fallen into some disuse since the fifties, when it was more popularly used in treating developmentally disabled persons. This is not to say that it is not used by some. For example, Zisfein and Rosen (1972) state that Elwyn Institute has developed an excellent "Personality Adjustment Training" Program based on a structured group counseling model. Nevertheless, group counseling, like individual counseling, is not generally provided by mental health specialists in the community who often lack both the time and inclination to work with this group.

The special need of the developmentally disabled older and aged adult for day treament programs has, in part, contributed to this gap in service as the activity provided often becomes a substitute for counseling or psychotherapy. Then again "counseling" is often considered synonymous with case management or coordination. This increases the likelihood that it is not employed as often as it might be with the developmentally disabled population.

The mental health specialist needs to be made aware of and encouraged to provide counseling and psychotherapy to aging and aged developmentally disabled persons, if not directly, then through supervising others in that effort.

## Clinical Assessment and Advocacy

Over an eight month period, the Aging/Developmental Disabilities Project staff has advocated on behalf of a seventy year-old man who had been wrongly diagnosed as "mentally retarded" and legally classified as "mentally incompetent." Through the utilization of clinical assessments and the support of the Legal Aid Society, his legal rights were restored. The issues which became evident in working with this client are relevant to all aging and aged developmentally disabled people.

Mr. R., or "the elderly gentleman," as he came to be known, was referred to the Institute for the Study of Mental Retardation and Related Disabilities (ISMRRD) by a community based senior citizens program. Responsibility for the case was accepted by the Aging/DD project. The project advocated on Mr. R.'s behalf within the Institute's clinical program, and later, within the probate court system. The project coordinated and participated in the clinical assessments, and provided follow-up and supportive counseling to the client.

The community program which referred Mr. R. for diagnosis provides volunteer supportive services to neighborhood residents who are aged. The agency became concerned about their client's annoying behavior and feared that it would incite the community to institutionalize him. He was described by his family doctor as impulsive, childish, and as having poor frustration tolerance. A number of other persons, which included the doctor's nurse, public health visiting nurses, and department of social services social workers, described Mr. R. as depressed and as having a bad temper. He was known to threaten suicide daily; however, he was not considered a serious suicide risk. He complained bitterly about 1) his legal guardian, whom he said did not give him enough money and physically abused him, and 2) the tenant upstairs who made too much noise. He was known for "burning people out" with his incessant telephone calls and inappropriate telephone behavior (he hung up abruptly, didn't listen, and shouted into the receiver). At the time, Mr. R.'s legal guardian was opposed to having his ward go through an intensive diagnostic process at ISMRRD. The guardian thought it was not worthwhile because Mr. R. would not change.

However, because of Mr. R.'s insistent interest in moving to a smaller home, the Senior Center Agency, with the help of Legal Aid, brought the case before the local probate court. At the hearing, Mr. R.'s guardian was required to prepare the necessary application forms in order for Mr. R. to go through the diagnostic process at ISMRRD. Some of the questions answered were:

1) Is Mr. R. capable of continuing his independent living situation in the community? If so, under what conditions?

2) Should he be placed in a group home or be institutionalized, or a combination of both?

3) Is Mr. R. retarded? (This is a question which he himself had asked). Is he emotionally disturbed? Is it a combination of the two? Or does he suffer from chronic brain syndrome associated with a pathological aging process?

4) What type of treatment should he receive?

Recommendations stemming from the diagnostic process were to be used by the court to determine a course of action for Mr. R.

Mr. R. was evaluated by the following disciplines: psychology, psychiatry, dental hygiene, occupational therapy, nutrition, and social work. They carried out individual or joint evaluations. Reports and a summary were given to the probate court and selected evaluators were asked to testify. Unlike the clinical procedure, which is carried out for children during a week's period of time, the evaluations for Mr. R. were carried out over a three-week period at ISMRRD and at Mr. R.'s home. His uniqueness required that the evaluating clinicians be adaptive and creative in designing or selecting testing materials.

Mr. R., who had been labeled mentally retarded since about age twelve, was found to perform in the average to above average range of intelligence for his age group. This level of ability was shown despite his significant hearing problems and his difficulty in dealing with a new and threatening interpersonal situation. His overall ability to articulate concepts was less than would be expected for his

IQ, but this disparity was not attributable to organicity but rather to a specific short-term memory problem which is not unexpected at his age.

Mr. R. showed no evidence of chronic brain syndrome; he was not seen as psychotic nor suffering from a primary depressive disorder. He was seen as a highly egocentric man with certain characterological ways of manipulating people and avoiding anxiety. As his most frequent interactions had been with people who, in one way or another, had attempted to change his life, he often perceived them negatively, feeling that they are trying to control his life.

He was seen as a person who projected his anger and frustrations onto others and who exhibited mild paranoia; however, there was no indication that this difficulty in handling his aggression made him a threat to himself or others. It was also believed that his paranoia could not be viewed as abnormal for someone with a severe hearing loss or someone who had been inaccurately viewed as mentally retarded for as long as he had been.

It was concluded that Mr. R. was not mentally ill. Due to a combination of his projection of anger onto others, his considerable demands upon people for support, his personal habits, and peoples' impressions about his mental abilities, he was more disturbing to others than he, himself, was disturbed.

A critical issue which came out of the clinical assessment and advocacy work with Mr. R. was the difficulty in identifying aged developmentally disabled clients because of previous errors in diagnosis. It also highlighted the need for community education regarding developmental disabilities. It illustrated a number of other significant areas of concern: (1) the incorrect application of "mentally retarded" and "mentally incompetent" labels; (2) the need for accurate diagnosis; (3) the need for change in probate codes concerning guardianship for aged, mentally retarded, and mentally ill persons; (4) the need for meaningful treatment and case management; (5) the need for appropriate referral to agencies; (6) the need for protecting the human and civil rights of aging and aged developmentally disabled persons; (7) the need for social tolerance of deviance; and (8) the infantilization of and other misconceptions about aging and aged developmentally disabled persons.

The appropriate identification of aging and aging developmentally disabled clients is a problem faced by all five aging/DD's projects and programs seeking demographic information. A model regarding clinical assessment and advocacy will be potentially useful to programs and agencies throughout the country.

## Conclusion

A great deal of work has already been done in developing a philosophical position with regard to the human and civil rights of developmentally disabled persons, but more work is required to design meaningful new programs which actually incorporate and reflect these values. This is particularly true for programs serving the aging and aged developmentally disabled population as this group of persons is affected by two negative stereotypes.

The work done by the project in carrying out the demonstration programs described above serves to illustrate the fact that innovations geared to meet the needs of this group can be incorporated into existing agency programs. The therapeutic art interventions, the group counseling, and the advocacy models are not "uniquely" innovative. They have all been done before in different ways, but they have not necessarily been adapted to promote the well-being of aging and aged developmentally disabled people.

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# CURRICULUM DEVELOPMENT FOR PERSONNEL INVOLVED WITH THE AGING DEVELOPMENTALLY DISABLED

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The beginning of the curriculum development aspect of the Nebraska project resulted from a recognition that the needs of the aging developmentally disabled were not addressed in typical university course offerings. Many departments included content on aging or developmental disabilities, but integration of the two areas was rare or non-existent. Students who were interested in developmental disabilities from a gerontological perspective were forced to obtain information in the areas independently, and then integrate the material on their own. Awareness of the unmet need for systematic articulation of developmental disabilities and aging prompted the Aging/DD Project of University of Nebraska to orient a major portion of its activites toward interdepartmental, integrated curriculum development. Major concerns included the specific needs and potential of older persons who are developmentally disabled as well as the provision of information to individuals and agencies who are in positions to work most effectively toward changing existing systems of institutionalization.

A number of stages and needs were identified as being appropriate for the completion of various portions of this process and reaching the goal of integrating aging/developmental disabilities curriculum offerings. Initially, the process included informing faculty and staff at the University of Nebraska of the lack of integrated course materials. Interest was expressed by faculty in various departments. From this group, individuals were selected to develop instructional materials and models through course offerings, inservice workshops and training programs. The consistent purpose of these activities was to identify and coordinate content that could relate to both aging and developmental disabilities. The development of an aging/developmental disabilities curriculum within the University of Nebraska reflects a unique orientation.

The Gerontology Program at the University of Nebraska at Omaha is housed within the College of Public Affairs and Community Service. As a program within the University System (as distinguished from a department or school), prescribed responsibilities allow for increased interdisciplinary interaction and university-wide involvement. The program provides service to agencies and organizations concerned with the aging population in the form of continuing education programs, research on the needs of the aging community, and technical assistance designed to improve the quality of service delivered by human service organizations.

A basic difference between the Gerontology Program and departments within the university is this problem-centered rather than discipline-centered approach. This allows for multidisciplinary curriculum development through a university base rather than the more usual departmental/discipline base. Students in the program typically major in a number of areas such as counseling, social work, psychology, or public administration while at the same time obtaining a certificate of specialization in gerontology. Gerontology courses are often cross-listed between two or more departments and faculty with a broad range of expertise, experience and interests are utilized.

With this orientation in mind, the project began an investigation of the curriculum needs and subsequently initiated the development of course units within existing courses, workshops, and printed materials which could be disseminated to human service agencies involved in serving individuals who are both aging and developmentally disabled.

Initially, faculty within the university system were assessed to determine which departments might make significant contributions to the development of the curricula. The initial list included counseling and guidance, dentistry, health education, physical education, psychology, recreation, social work, and special education. One of the major developments of the first year of the project was the completion of a bibliographical index of information available which integrated aging and developmental disabilities. This was made possible through a programmed retrieval system and the assistance of faculty from the participating departments. The resulting list of publications includes material relating to aging/developmental disabilities from a wide variety of fields and disciplines.

The next portion of the project involved faculty who were interested in developing departmental offerings on a variety of levels integrating the aging process and the needs of the developmentally disabled. Faculty from all three campuses of the university were provided released time to develop various aspects of curriculum which might then be incorporated into departmental offerings. A variety of curriculum offerings were proposed. These included complete course offerings, units within existing courses, perceived competency needs, workshops, inservice programs, and seminars to be conducted on and off campuq. In addition, manuals and "guidesheets" were developed for regional and national dissemination. Manuals are basically descriptive texts explaining plans and procedures for completing activity units or programs conducted by service personnel. As an example, "Physical Activity for the Developmentally Disabled Elderly" discusses activities and programs for the implementation of these activities. Guidesheets are compact handout materials which might be disseminated at workshops or inservice training programs. They focus on specific information of a "how to" nature, with a single concept being developed.

The actual task of developing the curriculum, regardless of form, was left to the expertise of the faculty. Following is an initial listing of courses offered within the university system which have been developed and/or modified to include information specific to aging and developmental disabilities:

Psychology Department

Life Span Psychology
Practicum

The Counseling and Guidance Department

Directed Reading in Counseling and Gerontology
Practicum Internship

The School of Social Work

Introduction to Social Welfare
Social Work as a Profession
Social Work Practices in Mental Health
Practicum

The Department of Health Education

Health Aspects of Aging

The Department of Recreation

Recreation Programs for the Mentally Ill
and the Mentally Retarded
Recreation for the Aging
Introduction to Therapeutic Recreation
Education for Leisure

A number of workshops and inservice programs have been developed or are near completion through a variety of departments in addition to several manuals and guide sheets which are currently being finalized. These include:

Recreation for the Aged - (workshop)
Recreation for the Aged - (manual)
Physical Activities for the Developmentally Disabled Elderly
- (workshop)
Physical Activities for the Developmentally Disabled Elderly
- (manual)
Sport and Recreation for the Disabled - (workshop)
Mental Retardation and Developmentally Disabled Manual
- (manual)
Leisure Counseling for the Mentally Retarded - (workshop)
Leisure Educational Counseling for the Mentally Retarded
- (guidesheet)

Other departments have become aware of the need for including information on aging and developmental disabilities and have indicated that steps are being initiated to develop a more comprehensive integration of materials within their respective disciplines.

The curriculum offerings listed above were developed by faculty in existing departments within the University of Nebraska. The courses and materials are seen as an initial step in the establishment of a sound curriculum for students interested in aging aspects of developmental disabilities. Additional course offerings and curriculum modifications are expected in the near future although the curriculum development aspects of the project are near completion. Courses which at this time are anticipated as interdepartmental in nature and deal to some extent with aging/developmental disabilities are: (1) Communication Problems of the Aging Individual; and (2) Design of Human Service Systems (two semesters).

As syllabi and manuscripts have been completed, the involved faculty have been informally questioned regarding problems, drawbacks, and general concerns regarding their individual contributions.

One evolving need is the coordination of all curriculum development through a central committee. Concern has been expressed that overlap among departmental offerings may exist and more detailed syllabi are needed in order to assure that sources complement rather than duplicate each other. Therefore, a committee has been established to screen project materials in order to better coordinate products submitted by different departments. This committee should also be able to recruit and advise students as well as publicize the total project.

The project's goal for the future is the testing of these curricular developments, determining the extent to which students find the course work and materials useful and the receptivity to the final product--the educated student--by community agencies which are potential employers. Only time will clarify the final outcome, but we have high hopes that the student with an integrated exposure to these fields will provide a new resouce for the expansion and improvement of community services to the aged developmentally disabled.

# THE OREGON AGED DEVELOPMENTALLY DISABLED POPULATION: GETTING IT ALL TOGETHER FROM A DATA BASE

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Since passage of federal legislation confiming the rights of developmentally disabled (DD) individuals to enjoy the least restrictive environment possible, efforts have increased to implement policies, procedures and programs that will expand the quality of life for these individuals. Conferences and training efforts have surfaced along with the slower emergence of a body of literature deriving from a range of professional journals.

At the same time many conditions deter the pace and quality of implementation, such as:

1) No comprehensive data base is available about the adult developmentally disabled (ADD) population. Planners tend to rely on statistical estimates of population magnitude derived from a procedure reported in Stevens & Heber (1952);
2) Few service providers or professionals at the training-of-providers level can articulate a conceptual framework about ADDs that directs their work, because theoretical formulations about aging in general, as well as about ADD aging, are meager. Instead, a diversity of personal beliefs coupled with direct personal experiences with ADDs seems to provide the basis for a best estimate as to ADDs' needs; and
3) Communication networks between agencies and individuals are nonexistent or tend to break down. Opinions of ADDs them-

> selves are sought infrequently when policies for and about them are being considered. There appears to be little recognition of the ways in which administrative structure could encourage vertical as well as horizontal lines of communication in both inter- and intra-agency efforts.

The three goals of the Oregon project attempt to address these deterrents. The project's goals include: (1) comprehensive data collection at state, county and individual levels; (2) professional curriculum development involving consciousness-raising and clinical training across a spectrum of disciplines; and (3)consultation at professional and administrative levels.

In this paper the results and implications of the project data collection efforts will be presented.

For three days this conference will consider questions, issues, training efforts and service delivery systems that relate to the ADD population. One task we have been given is to identify and prioritize once again the needs of ADDs. A need, by definition, is a condition marked by the lack of something, and the making of such determinations becomes a decision-making task. Who makes these determinations about absence of a need and what kind of evidence is used to support the selection? Some professionals rely upon broad experience in the field; some intermix advocacy and personal bias during the need identification task. Nowhere in all the prioritizations has a statement accompanied the listing indicating the possible relation of geographic, economic or population variables to the needs selected.

## Prioritized Listing of Needs by ADDs Made by Five Professional Groups

Table 1 shows sets of prioritized listings of the needs of ADDs made by five difference professional groups.

We see that housing and employment categories are loosely referred to in all listings. The following are some hypotheses that these listings suggest: (1) possibly the referrent group(s) of concern to these prioritizers require specification (e.g., MR's; MR's in 21 to 40 year age group, CP's at all ages, etc.); (2) possibly prioritizers might have been influenced by the different geographic, social and population conditions they are in; and (3) perhaps the prioritizers started with different conceptual orientations. Other hypotheses may become apparent as this conference attempts still another need prioritization.

The Oregon project determined to improve upon this situation from the outset of its work (October, 1967). Then it was found that little ordered, organized, or standardized knowledge about the state's ADD population was available at governmental or service-provided levels. The plan was to collect data about this population in a simple manner using standardized and reliable procedures. Ony two questions were investigated: (1) How many ADDs are there in Oregon? and (2) What is their current status? From this data base, then, the project expected to be able to specify the needs of its target populations.

Two survey instruments were designed to answer the questions. Each was viewed as providing a potential model for use in other states or regions wishing to obtain similar descriptive information. One survey sought simple demographic information--age by diagnosis, by county, and also identification of existing workshops

## TABLE 1

Prioritized Listings of Needs by ADD's Made by Five Professional Groups

(First five priorities only)

University of Michigan Conference on Gerontological Aspects of Mental Retardation (MR).

1. Health related needs
2. Social and emotional needs
3. Housing
4. Vocational
5. Avocational

Oregon State DD Council for 1978-79 Biennium.

1. Education
2. Family support
3. Prevention
4. Treatment (medical)
5. Living arrangements

Oregon County #1

1. Sheltered employment
2. Training (not specified)
3. Transportation
4. Special living arrangements

Oregon County #2

1. Sheltered workshop
2. Residential
3. Activity center
4. Respite care
5. Homemaker

Oregon County #3

1. Public education
2. Group home coordinator
3. Activity center
4. sheltered workshop
5. Semi-independent living

## TABLE 2

Total CP and MR Populations Identified by Demographic Survey

(Including Age and Locus of Residence)

Total CP Population

| | 21-40 yrs | 41-60 yrs | 61+ yrs |
|---|---|---|---|
| Community | 105 | 29 | 5 |
| Institution | 142 | 28 | 4 |

Total MR Population

| | 21-40 yrs | 41-60 yrs | 61+ yrs |
|---|---|---|---|
| Community | 1,569 | 505 | 221 |
| Institution | | 206 | 30 |

and activity centers in each county. The second consisted of a 47-item, comprehensive, follow-up questionnaire concerning the status and quality-of-life of identified ADDs in Oregon. No names were required for either survey. Ten counties of the 36 counties within Oregon were selected for this intensive probe because they reflected one or more of the geographic, economic and population patterns of the state. DD Service Coordinators in each county selected provided information. Clearance for access to this information was obtained at the state ADD office level. No clearance could be obtained for access to nursing home residents or to their nursing home records. All residents 41 years of age or older in both state institutions for the DD were surveyed. Because of the minimal results of a well-funded outreach project conducted by the Oregon Epilepsy League to identify all individuals having epilepsy, this diagnostic category was not included in the present study. Similarly, project efforts to locate adults labeled autistic produced few results. A childhood label of autism changes to one of retardation or schizophrenia upon attaining adult status. The diagnostic category of adult autism was also excluded from the study. Included in both surveys were all cerebral palsied (CP) individuals 21 years of age and over and all mentally retarded (MR) individuals 41 years of age and over. Available at the University Oregon Health Science Center, Crippled Children's Division, are records covering a 30-year time span for over 700 adult CP individuals who had been followed in clinics there until reaching 21 years of age. These records contain extensive medical and less extensive social and educationl information. Such data were seen as providing a rich source of historical information that might contribute to conceptualizations about the life-span development of CPs and to an evaluation of the service delivery systems used. For this reason CPs in the 21-40 age group were added to the adult-aging sample.

Of the 36 counties in Oregon, 24 had DD service coordinators while two counties were paired and served by one coordinator. A variety of reasons, political, understaffing, inability of DD coordinators to handle large quantities of statistical data, etc., explain why the remaining counties having DD Service Coordinators did not report.

Table 2 shows total CP and MR populations identified by the demographic survey in both community and institutional settings. The data are given as frequencies.

Both populations show rapid decline with increasing age. Thirty-three percent or more of both community-based CPs and MRs 21-40 years of age disappear between ages 41-60. The rate of decline is even higher after age 61 years of age when only 17% of the CPs and 50% of the MRs remain. This pattern is relatively similar for both institutionalized populations with an even greater decrease in MRs after 61+ years.

The rate of this decline does not follow that of the normal population. If the needs of both populations are to be identified accurattely, the causes of this death/disappearance pattern need to be better understood. Is it, in fact, a matter of shorter life span, of modes of treatment and intervention given in early years, of severity of condition, or of neglect?

Total CP and MR Populations in Each County Reporting by Age Group

## TABLE 3

### Total CP and MR Populations in Each County Reporting, by Age Group

| COUNTY | 21-40 |  | 41-60 |  | 61+ |  |
|---|---|---|---|---|---|---|
|  | MR | CP | MR | CP | MR | CP |
| Baker | 17 | 3 | 5 | - | 4 | - |
| Benton | 81 | 10 | 15 | - | 11 | - |
| Clackamas | 92 | 6 | 71 | 5 | 59 | 2 |
| Clatsop | 23 | - | 17 | 1 | 10 | - |
| Columbia | 46 | 4 | 8 | 1 | 8 | - |
| Coos | 135 | 5 | 18 | 2 | 10 | - |
| Curry | 44 | 2 | 5 | - | 2 | - |
| Deschutes | 32 | 10 | 9 | - | - | - |
| Douglas | 56 | 10 | 20 | - | 5 | - |
| Jackson | 128 | 2 | 33 | - | 8 | 1 |
| Josephine | 99 | 4 | 42 | 2 | 2 | - |
| Klamath | 57 | 7 | 35 | 6 | 12 | - |
| Lake | 12 | - | 1 | - | 2 | - |
| Lane | 272 | 25 | 59 | 1 | 13 | - |
| Lincoln | 36 | 1 | 3 | - | - | - |
| Linn | 70 | 4 | 37 | 2 | 26 | - |
| Morrow | 10 | - | 2 | - | 1 | - |
| Polk | 92 | 3 | 46 | 2 | 17 | - |
| Umatilla | 52 | 3 | 26 | 1 | 8 | 1 |
| Washington | 157 | 5 | 25 | 4 | 6 | - |
| Yamhill | 58 | 1 | 28 | 2 | 18 | - |
| TOTALS | 1,569 | 105 | 505 | 29 | 221 | 5 |

Table 3 presents these same total sample data for each county reporting.

What explains the wide variability observed? Do the county's prioritized needs lists reflect number of MRs and CPs identified, economic, geographic and cultural conditions in the county? Two conditions unique to particular counties may indicate the relevance of this question: one county contains the highest concentration of nursing homes of all counties in the state, a second contains the only sheltered workshop for CPs in the entire state.

Still another problem, one with funding implications, is presented by these demographic data. The procedure for estimating total MR and CP populations in any area has been to use percentage of total general population (3%), a proportion arrived at in a carefully-reasoned article by Stevens and Heber (1958). Even if one adds to the total population figures already shown here another 3,000 ADDs for the two large counties in Oregon not reporting, the result still does not approach 3% of the general population in Oregon. This discrepant finding is beginning to grow in the awareness of state officials concerned with ADD services. They now hypothesize that the adult ADD population in Oregon may include only 1% of the general population. This project's incomplete data suggests it to be .75% or a little more. Tarjan (1974)[1] presents evidence for a 1% national estimate. Accurate population estimates and needs assessments, for policy making and for funding decision, seems imperative. Concomitantly, service providers, knowing individual ADDs and their lifestyle, press for improvement in the quality of life for each client. Their advocacy, personal concern, and years of experience does supply a necessary but narrow-based focus for identifying client needs. Perhaps both sources of information become essential for any valid needs assessment.

Understanding in data language the current life circumstances of identified ADDs residing in community and institutional settings was attempted by surveying individuals on 47 items or dimensions. The results for only six of these dimensions will be presented here. These include: age, sex, diagnosis (primary or secondary), type of residence, and independent money handling ability. Outcomes will be shown singly and in combination. For the more complex combinations the results can only be viewed as simplistic efforts at cluster analysis. Both populations of CPs and MRs are smaller than those included in the demographic survey due to cost of staff required for this more time-consuming effort. Responses to items were derived from DD service coordinators, state institution staff, and where possible, from direct interviews with ADDs. The survey included all residents of both state institutions.

## Total CP Sample Surveyed: Sex, Age, Community and Institution

Table 4 shows the total CP sample surveyed with furthr breakdown by community or institution residence, sex and age.

There are 24 more males than females in the total CP sample. This skew affects all age categories: 53% of sample are males, 47% females. The results show that 80% of the 66 male CPs residing in the community are in the 21-40 year group, and 18% in the 41-60 year group. Among the 44 female CPs, 21-40 years of age, 59% live in the community, and 36% of the 41-60 year group. One might wonder whether younger male CPs either have less severe conditions or whether more

## TABLES 4A, 4B & 4C

Total CP Sample Surveyed by Comprehensive Questionnaire,

Including Sex and Age

### Total CP Sample

Table 4A

| | 21-40 | 41-60 | 61+ | TOTAL |
|---|---|---|---|---|
| Male | 119 | 26 | 5 | 150 |
| Female | 102 | 20 | 2 | 134 |
| TOTAL | 221 | 56 | 7 | 284 |

### Community CP Sample

Table 4B

| | 21-40 | 41-60 | 61+ | TOTAL |
|---|---|---|---|---|
| Male | 53 | 12 | 1 | 66 |
| Female | 26 | 16 | 2 | 44 |
| TOTAL | 79 | 28 | 3 | 110 |

### Institutional Sample

Table 4C

| | 21-40 | 41-60 | 61+ | TOTAL |
|---|---|---|---|---|
| Male | 66 | 14 | 4 | 84 |
| Female | 76 | 14 | 0 | 90 |
| TOTAL | 142 | 28 | 4 | 170 |

effort may have been spent in trying to make them independent.

Institutionalized male CPs in the 21-40 year group constitute 78% of the total sample, while almost 85% of the female CPs 21-40 years of age are institutionalized. The conclusion, again, seems to be that more females are institutionalized than males at the younger adult years.

### Total MR Sample Surveyed: Sex, Age, Community and Institution

Table 5A, 5B and 5C show results on this same dimension for the total MR population, but only for two age groups, 41-60 years and 61+ years.

Total sample size for both sexes differs by 15 individuals--15 more males than females. This affects all data shown. No clear trend occurs even when looking at degrees of MR by age group. Many more male 21-40 year old mild MRs reside in both community and institution than do females. This reverses in the 61+ year old group of mild MRs when females exceed males.

How can the clear male-in-the-community pattern for CPs and the mixed pattern for MRs be explained? By cultural views concerning the goal of independence for men, by differences in degree of disability that are sex related?

It was hypothesized that presence or absence of a secondary diagnosis should contribute significantly to an individual's status and life-course.

### CP Community and Institutional Samples With and Without a Secondary Diagnosis

Tables 6A and 6B show the results of this dimension for both CP and MR populations

TABLES 5A, 5B & 5C

Total MR Sample Surveyed by Comprehensive Questionnaire

Including Sex and Age

Total Sample

Table 5A

| | 41-60 yrs. | | | | 61+ yrs. | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | Mild | Mod. | Sev. | Pro. | Mild | Mod. | Sev. | Pro. | TOTAL |
| Male | 47 | 51 | 54 | 34 | 12 | 15 | 7 | 12 | 232 |
| Female | 30 | 55 | 49 | 37 | 19 | 22 | 13 | 11 | 236 |
| TOTAL | 77 | 106 | 103 | 71 | 31 | 37 | 20 | 23 | 468 |

Community Sample

Table 5B

| | 41-60 yrs. | | | | 61+ yrs. | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | Mild | Mod. | Sev. | Pro. | Mild | Mod. | Sev. | Pro. | TOTAL |
| Male | 29 | 33 | 16 | 1 | 8 | 11 | 3 | 8 | 109 |
| Female | 21 | 31 | 15 | 5 | 18 | 19 | 12 | 3 | 123 |
| TOTAL | 50 | 64 | 31 | 6 | 26 | 29 | 15 | 11 | 232 |

Institution Sample

Table 5C

| | 41-60 yrs. | | | | 61+ yrs. | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | Mild | Mod. | Sev. | Pro. | Mild | Mod. | Sev. | Pro. | TOTAL |
| Male | 18 | 18 | 38 | 33 | 4 | 4 | 4 | 4 | 123 |
| Female | 9 | 24 | 34 | 32 | 1 | 4 | 1 | 8 | 113 |
| TOTAL | 27 | 42 | 72 | 65 | 5 | 8 | 5 | 12 | 236 |

## TABLES 6A & 6B

### CP Community and Institutional Samples

### With and Without a Secondary Diagnosis

**Table 6A**

Community Sample

| SECONDARY DIAGNOSIS | 21-40 | 41-60 | 61+ | TOTAL |
|---|---|---|---|---|
| No secondary | 28 | 12 | 2 | 42 |
| Mild MR | 16 | 5 | 1 | 22 |
| Moderate MR | 15 | 4 | 0 | 19 |
| Severe MR | 5 | 1 | 0 | 6 |
| Profound MR | 4 | 0 | 0 | 4 |
| Epilepsy | 3 | 0 | 0 | 3 |
| Other (Medical) | 6 | 5 | 0 | 11 |
| Unknown | 2 | 1 | 0 | 3 |

**Table 6B**

Institutional Sample

| SECONDARY DIAGNOSIS | 21-40 | 41-60 | 61+ | TOTAL |
|---|---|---|---|---|
| No secondary | 1 | 1 | 0 | 2 |
| Mild MR | 4 | 1 | 0 | 5 |
| Moderate MR | 21 | 2 | 0 | 23 |
| Severe MR | 23 | 4 | 1 | 27 |
| Profound MR | 71 | 16 | 3 | 87 |
| Epilepsy | 18 | 3 | 0 | 21 |
| Other (Medical) | 4 | 0 | 0 | 4 |
| Unknown | 0 | 0 | 0 | 0 |

Of the 79 community CPs 21-40 years of age, 28 or 35% had no secondary diagnosis, 62% did. Two-thirds of those with a secondary diagnosis had either mild or moderate retardation. In the 41-60 year group of 28 individuals, 12 or 43% had no secondary diagnosis while 53% did. Sixty percent of the latter had similar diagnosis of mild or moderate MR. Two of the three CPs 61 years or older had no secondary diagnosis. It appears that a CP individual with secondary mild/moderate retardation is likely to reside in the community.

Institutionalized CPs show a different trend. Only one of the 142 CPs 21-40 years of age had no secondary diagnosis--141 other individuals did. Seventy-one or 50% were profoundly retarded, 16% were severely retarded and 15% were moderately retarded. Epilepsy was the secondary diagnosis of the next largest group, 13%. The 41-60 year group follows the same pattern as the younger group. All three of the 61-year group were profoundly or severely retarded. It appears, then, that CPs having a more severe secondary diagnosis of MR or of epilepsy are likely to be institutionalized.

This conclusion is not so for the two MR age groups; their pattern is consistent but different.

## MR Community and Institutional Sample with and without a Secondary Diagnosis

Tables 7A and 7B show that in the community sample of 231 MR individuals and across all four degrees of retardation, 52% carry no secondary diagnosis. "Other" medical diagnoses constitute the next largest type of secondary diagnosis, 31%. Epilepsy constitutes 9% of the secondary diagnosis of this total group. For the institutionalized MR sample of 236, the pattern closely follows that of the com-

# TABLES 7A & 7B

## MR Community and Institutional Samples

## With and Without a Secondary Diagnosis

Table 7A — Community Sample

| | 41-60 | | | | 61+ | | | | |
|---|---|---|---|---|---|---|---|---|---|
| SECONDARY DIAGN. | Mild | Mod. | Sev. | Pro. | Mild. | Mod. | Sev. | Pro. | TOTAL |
| No Secondary | 22 | 42 | 15 | 2 | 14 | 16 | 7 | 3 | 121 |
| Cerebral Palsy | 2 | 1 | 1 | 1 | 0 | 0 | 1 | 0 | 6 |
| Epilepsy | 9 | 2 | 3 | 2 | 1 | 1 | 2 | 1 | 21 |
| Other (Medical) | 17 | 14 | 10 | 0 | 10 | 9 | 4 | 7 | 71 |
| Unknown | 0 | 5 | 2 | 0 | 1 | 3 | 1 | 0 | 12 |

Table 7B — Institutional Sample

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| No Secondary | 12 | 20 | 40 | 30 | 1 | 5 | 4 | 3 | 116 |
| Cerebral Palsy | 0 | 0 | 0 | 3 | 0 | 0 | 0 | 1 | 4 |
| Epilepsy | 5 | 10 | 9 | 15 | 0 | 0 | 0 | 4 | 43 |
| Other (Medical) | 8 | 10 | 13 | 13 | 4 | 1 | 0 | 1 | 50 |
| Unknown | 1 | 2 | 9 | 4 | 0 | 2 | 1 | 3 | 22 |

munity group with epilepsy showing as the secondary diagnosis for a somewhat larger number, 18%. It appears that the physiological and medical conditions that accompnay a primary diagnosis of MR differ markedly from those of the CP population. Also many more MRs have just one diagnosis.

## Type of Current Residence of CP and MR Samples by Age and Sex

Type of current community residence was considered to be another dimension of major importance. Tables 8A and 8B show these data for both CP and MR community samples.

In the total CP sample of 110 and across all three age groups the trend appears similar. The largest number 47, or 43%, live with family; next they live with roommate or spouse, then in one of the supervised group or apartment facilities, and then in nursing homes. The smallest number, 8%, live alone. At 41 years of age family residence still occupies first place for roughly 40%, while nursing home residence replaces group-type living arrangements for 25%. Independent living or living with a spouse also covers 25% of this age group. For the three CP individuals over 61 years, no one type of residence is preponderant.

Again the MR sample differs from the CP group. For the total MR sample, and across the two age groups and all degrees of retardation, the largest number 63 or 27%, reside in one of the supervised group or apartment facilities. Only 13% reside in a family setting. In all types of residency permitting some degree of independent living there are more males than females.

The outstanding difference in the data between CPs and MRs with respect to home/group type residence speak for themselves. The two

## TABLES 8A & 8B

Type of Current Residence of CP and MR Samples by Age and Sex

Table 8A

CP Sample

| TYPE RESIDENCE | 21-40 |  | 41-60 |  | 61+ |  | TOTALS |
|---|---|---|---|---|---|---|---|
|  | M | F | M | F | M | F |  |
| Alone | 4 | 1 | 2 | 1 | 0 | 1 | 9 |
| Family | 26 | 10 | 5 | 6 | 0 | 0 | 47 |
| Roommate/Spouse | 7 | 9 | 1 | 3 | 0 | 0 | 20 |
| Satellite Apt. | 3 | 1 | 0 | 0 | 0 | 0 | 4 |
| Foster Home | 4 | 2 | 1 | 0 | 0 | 0 | 7 |
| Group Home | 4 | 0 | 1 | 1 | 0 | 0 | 6 |
| Home for Aged | 0 | 0 | 0 | 0 | 0 | 1 | 1 |
| ICF Nursing Home | 4 | 2 | 2 | 3 | 1 | 0 | 12 |
| SNF Nursing Home | 1 | 1 | 0 | 2 | 0 | 0 | 4 |

Table 8B

MR Sample

| TYPE RESIDENCE | 41-60 |  |  |  |  |  |  |  | 61+ |  |  |  |  |  |  |  | TOTALS |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
|  | Mild |  | Mod. |  | Sev. |  | Pro. |  | Mild |  | Mod. |  | Sev. |  | Pro. |  |  |
|  | M | F | M | F | M | F | M | F | M | F | M | F | M | F | M | F |  |
| Alone | 6 | 4 | 3 | 2 | - | - | - | - | - | 1 | - | - | - | - | - | - | 16 |
| Family | 5 | 7 | 6 | 4 | 3 | 1 | - | - | - | 1 | - | - | - | 1 | 1 | - | 29 |
| Roommate/Spouse | 3 | 3 | 2 | 2 | - | - | - | - | - | 1 | - | - | - | - | - | - | 11 |
| Satellite Apt. | 1 | 1 | - | - | - | - | - | - | - | 1 | - | - | - | - | - | - | 3 |
| Foster Home | 5 | 1 | 8 | 9 | 4 | 2 | - | 1 | 2 | 3 | - | 1 | - | 1 | - | - | 37 |
| Group Home | 3 | 1 | 8 | 5 | 2 | - | - | - | 1 | - | 2 | 1 | - | - | - | - | 23 |
| Home for Aged | 2 | 1 | 3 | 4 | 1 | 4 | - | - | 2 | 4 | 3 | 4 | 1 | 1 | - | 1 | 31 |
| ICF Nursing Home | 3 | 1 | 3 | 4 | 6 | 8 | 1 | 2 | 1 | 7 | 6 | 9 | 2 | 6 | 7 | 1 | 67 |
| SCF Nursing Home | - | 2 | - | - | - | - | - | 1 | 2 | - | - | 2 | - | 3 | - | - | 9 |
| Other | - | - | - | 1 | - | - | - | 1 | - | - | - | 1 | - | - | - | 1 | 4 |
| Unknown | 1 | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | 1 |

groups probably should not be considered as one ADD unit when considering their housing needs.

Money Handling Ability of CP and MR Community Samples

The last dimension presented is that of independent money-handling ability. This means ability to manage credit, savings account, and checking with little or no assistance. Tables 9A and 9B show the results for the CP sample of 110 individuals.

Thirty-five percent are independent money handlers, 15% require others to manage their money affairs, and the remainder cannot, or do not, deal with money in a functional way.

Of the 39 money handlers 74%, or 29 persons, are in the 21-40 year age group; 31%, or 9, are in the 41-60 year group. This decrease in number may reflect the rate of decline by age group noted earlier rather than paucity of educational or cultural conditions in childhood. A large "unknown status" group of 26 individuals must be mentioned here.

MRs in the 41-60 age group total 151 individuals. Of these 20%, or 30 individuals, handle money independently. They fall primarily into the mild/moderate MR category. Here, too, there is a large "unknown status" group.

It seems reasonable to suggest that CPs show somewhat greater functional capacity to handle money than do MRs. The reasons for this, if it is the case, need further exploration and larger studies.

CP Community Sample: Ability to Handle Money, Education Level, Current Residence and Secondary Diagnosis

Attempting to produce clusters of individuals and groups along several dimensions concomitantly requires sample sizes far in excess

# TABLES 9A & 9B

## Money Handling Ability of CP and MR Community Samples

Table 9A

CP Sample

| DEGREE OF | 21-40 | | 41-60 | | 61+ | | |
|---|---|---|---|---|---|---|---|
| ABILITY | M | F | M | F | M | F | TOTALS |
| Credit, checking savings | 6 | 5 | 3 | 1 | - | - | 15 |
| Checking, savings | 13 | 5 | 2 | 3 | - | 1 | 24 |
| Others budget | 10 | 3 | 2 | 2 | - | - | |
| Realize value, not amounts | 4 | 3 | 2 | 4 | - | - | |
| No idea of money | 8 | 5 | 1 | 1 | - | - | |
| Unknown | 12 | 5 | 2 | 5 | 1 | 1 | |

Table 9B

MR Sample

| DEGREE | 41-60 | | | | | | | | | | 61+ | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| OF | Mild | | Mod. | | Sev. | | Pro. | | Mild | | Mod. | | Sev. | | Pro. | | |
| ABILITY | M | F | M | F | M | F | M | F | M | F | M | F | M | F | M | F | TOTALS |
| Credit, checking savings | 2 | 5 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 9 |
| Checking, savings | 13 | 3 | 2 | 3 | 1 | 0 | 0 | 0 | 0 | 5 | 0 | 0 | 0 | 0 | 0 | 0 | 27 |
| Others budget | 6 | 5 | 9 | 8 | 2 | 2 | 0 | 0 | 1 | 5 | 4 | 4 | 0 | 0 | 0 | 0 | |
| Realize value, not amounts | 3 | 4 | 10 | 13 | 4 | 0 | 0 | 0 | 2 | 0 | 2 | 6 | 1 | 4 | 1 | 0 | |
| No idea of money | 1 | 1 | 2 | 3 | 5 | 5 | 1 | 4 | 1 | 1 | 1 | 4 | 2 | 5 | 5 | 4 | |
| Unknown | 4 | 3 | 9 | 4 | 4 | 8 | 0 | 1 | 4 | 7 | 4 | 3 | 0 | 3 | 2 | 0 | |

of those reported here. The data shown in Tables 10A, 10B and 10C attempts to do this in a pilot effort only. Current status of CP and MR community populations of independent money handlers 41-60 years and 61+ years of age are presented along three other dimensions: educational level achieved, type of community residence, and presence or absence of a secondary diagnosis.

Tables 10A, 10B and 10C show that of the 28 CP individuals in the 41-60 year age community sample 9, Or 23%, are independent money handlers. Of these 9, 4 or 44%, acquired some grade school level education. The remainder reached high school levels or better. One-third of the 9 live with family, one-third live alone, and the remainder live in nursing homes or with spouse/roommate. Sixty-seven percent of the 28 CPs have no secondary diagnosis.

MR Community Sample: Ability to Handle Money, Educational Level, Current Residence, and Secondary Diagnosis

The MR community sample, shown in Talbes 11A, 11B, 11C show that of 151 individuals 30, or 20% were independent money handlers. Of these over one third had no specifiable education level, 23% a grade school level, and 20% a high school level. Their number is spread out relatively evenly over type of residence, e.g., a group type setting, living alone with roommate/spouse. Fifty-three percent show no secondary diagnosis.

It seems that MRs and CPs differ. Educational level achieved seems somewhat higher for CPs who tend to live with family and have no secondary diagnosis. MRs show a somewhat lower educational achievement level and live in more independent settings in the community. They also tend not to have a secondary diagnosis.

## TABLES 10A, 10B, 10C

### CP Community Sample Able to Handle Money Independently and Their Status with Respect to Educational Level Achieved, Type of Current Residence and Secondary Diagnosis

Table 10A Education

| EDUCATIONAL LEVEL ACHIEVED | 21-40 |  | 41-60 |  | 61+ |  |
|---|---|---|---|---|---|---|
|  | M | F | M | F | M | F |
| None/Not Specified | 3 | 2 | 0 | 2 | 0 | 0 |
| Primary | 1 | 0 | 1 | 0 | 0 | 0 |
| Grade School | 1 | 3 | 2 | 2 | 0 | 1 |
| High School/ Higher Education | 12 | 5 | 2 | 0 | 0 | 0 |
| Unknown | 2 | 0 | 0 | 0 | 0 | 0 |

Table 10B Residence

| TYPE OF RESIDENCE |  |  |  |  |  |  |
|---|---|---|---|---|---|---|
| Alone | 4 | 0 | 2 | 1 | 0 | 1 |
| Family | 5 | 4 | 1 | 2 | 0 | 0 |
| Roommate/Spouse | 4 | 5 | 1 | 0 | 0 | 0 |
| Satellite Apt. | 3 | 1 | 0 | 0 | 0 | 0 |
| Foster Home | 1 | 0 | 0 | 0 | 0 | 0 |
| Home for Aged | 0 | 0 | 0 | 0 | 0 | 0 |
| ICF Nursing Home | 1 | 0 | 1 | 1 | 0 | 0 |
| SNF Nursing Home | 1 | 0 | 0 | 0 | 0 | 0 |

Table 10C Secondary Diagnosis

| SECONDARY DIAGNOSIS |  |  |  |  |  |  |
|---|---|---|---|---|---|---|
| None | 12 | 4 | 4 | 2 | 0 | 1 |
| Mild MR | 7 | 2 | 0 | 0 | 0 | 0 |
| Moderate MR | 0 | 1 | 0 | 0 | 0 | 0 |
| Epilepsy | 0 | 1 | 0 | 0 | 0 | 0 |
| Medical | 0 | 1 | 1 | 0 | 0 | 0 |
| Unknown | 0 | 1 | 0 | 1 | 0 | 0 |

## TABLES 11A, 11B & 11C

### MR Community Sample Able to Handle Money Independently and Their Status with Respect to Educational Level Achieved, Type of Current Residence and Secondary Diagnosis

Table 11A — Education

| EDUCATIONAL LEVEL ACHIEVED | 41-60 yrs | | | | | | 61+ yrs | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Mild | | Mod. | | Sev. | | Mild | | Mod. | | Sev. | |
| | M | F | M | F | M | F | M | F | M | F | M | F |
| None/Not Specified | 6 | 2 | 1 | 1 | 1 | 0 | 1 | 3 | 0 | 0 | 0 | 0 |
| Primary | 0 | 1 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Grade | 4 | 2 | 1 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 |
| High School/ Higher Education | 4 | 1 | 0 | 1 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 |
| Unknown | 1 | 2 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |

Table 11B — Residence

| TYPE OF RESIDENCE | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Alone | 6 | 1 | 1 | 1 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 |
| Family | 1 | 1 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 |
| Roommate/Spouse | 3 | 3 | 1 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Satellite Apt. | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 |
| Foster Home | 2 | 1 | 1 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Group Home | 2 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Home for Aged | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 |
| ICF Nursing Home | 0 | 1 | 1 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 |
| SNF Nursing Home | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |

Table 11C — Secondary Diagnosis

| Secondary Diagnosis | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| None | 8 | 4 | 2 | 1 | 1 | 0 | 0 | 3 | 0 | 0 | 0 | 0 |
| CP | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Epilepsy | 2 | 1 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 |
| Medical | 4 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 |

## Conclusions

Accompanying each presentation of results for a specific dimension were brief summaries, hypotheses and questions to assist in integrating this mass of descriptive information. This information seems relatively accurate for Oregon but only suggestive for investigation elsewhere. From these first order efforts several more general conclusions can be posed. These are:

1) Life expectancy tables for MRs and CPs need to be developed. The still unanswered questions concerns the extremely steep decline in CPs between 21-40 years and 41-60 years, and 61+ years. This decline rate exceeds that expected in the normal population.

2) Results for CPs and MRs on each dimension indicate that the populations differ greatly on some dimensions. Their needs, histories, and expectancies suggest independent needs assessments rather than pooling both into an ADD population only.

3) Independent housing opportunities away from family supervision are less available to CPs than to MRs.

4) Further study of the status of CPs and MRs with/without a secondary diagnosis may provide important clues as to the degree of independence achieved by an individual DD in adulthood.

5) Efforts to assist females to achieve as much independence as males is suggested from some of the results, despite the sample skew toward more males.

6) The necessity for replication of the two surveys in a vari-

ety of communities and regions so that commonalities and differences between and among CPs and MRs can be accurately determined.

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# COMBATING REGRESSION: AN EDUCATIONAL APPROACH TO THE NEEDS OF THE AGING AND AGED DEVELOPMENTALLY DISABLED

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## Overview

The needs of the aging and aged developmentally disabled (AADD) have come to light as a result of several factors, not the least of which is the trend towards deinstitutionalization (Kriger, 1975). As we begin to focus on community living, it becomes apparent that a significant number of the AADD population lack skills which facilitate community adjustment, including: (a) adequate use of leisure time; (b) money management skills; and (c) daily living skills (i.e., cooking, cleaning, etc.) (Kriger, 1975; Nihira and Nihira, 1975a; Nove, 1975). This situation seems to be true not only of the recently deinstitutionalized AADD, but also of many of the handicapped adults who have been residing with relatives (Hofmeister, 1977).

Perhaps a major contributing factor to this lack of community adjustment skills has been the almost exclusive focus on meeting the "comfort" needs of the AADD (i.e., food, shelter, clothing) and skills associated with these needs (i.e., eating, toileting, dressing, etc.). Clearly, meeting comfort needs is important. However, the exclusive focus on such needs has resulted in the perpetuation of an extreme dependency relationship between the "caretaker" and AADD person (Kriger, 1975); and more seriously the precipitation of a regressive behavior pattern on the part of the AADD (Zigler and Balla, 1977). That is, rather than gaining new skills, the AADD ceases to use, and thus loses skills previously acquired.

Thus, if we are serious about community adjustment, it is critical that we expand our focus to include the educational needs, as well as the comfort needs and affective needs, of the AADD person. Only in this way can we break the cycle of dependence and regression.

In order to meet the challenge of providing for the educational needs of the AADD, two main issues must be addressed: method of delivery and method of instruction.

The delivery of educational services is particularly difficult with the AADD population, who are widely spread throughout the community in a variety of settings. The AADD may be located in a nursing home along with "normal" aged persons, in a group home, possibly with persons exhibiting a wide variety of handicapping conditions, or perhaps the adult developmentally disabled is residing with relatives, who are quite likely aged themselves.

Because the AADD population typically reside in a variety of locations over a large geographic area, it becomes difficult, and in some cases, impossible, to bring them to a central location to receive educational services from trained professionals. Thus, in most cases, the caretaker (i.e. group-home parent, relative, nusing home attendant) assumes the role of the "deliverer" of services. Unfortunately, the caretaker is often ill-prepared for this role, having little to no training or experience in instruction (Kriger, 1975; Nihira and Nihira, 1975b).

In view of the problems cited above, if a delivery system is to be effective with the AADD population, it must be capable of being implemented in a variety of settings by persons with limited training.

## Method of Instruction

Method of instruction is related to method of delivery. Were the AADD to be receiving instruction in a centralized location for example, then generalization would be of prime concern, (i.e., the instruction supplied in the centralized location should be capable of being generalized to the living sites). However, the group home staff are not interested in a generalizable curriculum, rather they are concerned with teaching specific skills that will be functional in their specific group home environment. The same is true of the nursing home coordinator or the relative of the developmentally disabled adult. Thus, the curriculum for the AADD must be composed of specific functional skills and the method of instruction must be adapted to a variety of environmental settings.

Since the instruction is to be conducted, in most cases on the job, by paraprofessionals, it must require a minimal amount of training to implement. The associated training material must be validated for use by paraprofessionals. The following characteristics of paraprofessional materials have been identified by Harrison (1975) and should be considered: (1) the materials should be targeted at specific learner needs; (2) the materials need to provide appropriate examples, practice, and systematic review of previously learned skills; and (3) learning tasks should be arranged in a hierarchical sequence. In addition, instruction and materials may be included to guide the tutor in interacting with the learner. These include mastery tests, criteria of performance, decision tables, etc.

The problem, then, centered around two issues: (1) the lack of validated instructional materials on daily living skills; and (2) the lack of a validated delivery system which facilitated the implementation of instructional materials by paraprofessionals in a variety of settings.

A technology already exists for developing instruction which can be delivered in a variety of settings by paraprofessional personnel. Hofmeister and Atkinson (1976) for example, developed a system of delivering instruction to severely handicapped children living in remote areas. Under this system parents provided education to their handicapped children via an instructional package and other support services. These instructional packages consisted of instructor manuals with specific directions, validated pupil materials in a highly sequenced format, and procedures for recording pupil performance. The materials were assembled in a highly replicable, self-contained format.

An effective instructional package technology has also been developed by Project MORE (Lent, 1975). Over twenty-two (22) packages in the areas of personal skills and safety skills have been developed and validated. As with packages developed by Hofmeister, Project MORE materials were designed to be used by persons of little or no training. Lent notes that the purpose of Project MORE "has always been to produce a useable product, one which enables anyone, regardless of training or artfulness, to produce the desired results in the persons being taught a skill" (p. 17).

The work of Lent (1975) and Hofmeister and Atkinson (1976) offer convincing evidence concerning the efficacy of the application of an instruction package technology in meeting the needs of the handicapped, particularly those residing in rural areas. Based on that evidence it would appear that many of the instructional needs of the AADD population might best be met through the application of this technology.

## Implementation of an Instructional Package Technology

The Exceptional Child Center at Utah State University was funded by the Developmental Disabilities Office, DHEW, to apply an instructional package technology to the educational problems of the aging and aged developmentally disabled. The specific project objectives were:

1) to assess the needs of aging and aged developmentally disabled individuals and their families in the rural target of Cache County, Utah;
2) to assess the resources which exist in the target area such as extension, public health, social service, and education personnel, who may assist in the delivery of needed services via families and local agencies;
3) to establish a team of Research and Development and Dissemination (RD&D) specialists to develop and validate intervention programs to remedy the assessed skill needs;
4) to develop and validate intervention programs in the area of daily living skills;
5) to train local and existing resource individuals to implement the validated instructional materials.
6) to assess the impact of the procedures and materials in the target area; and
7) to disseminate validated intervention programs to all areas within the rural target area and to other University Affiliated Facilities and other interested planning bodies.

In order to carry out the specific objectives, particularly objectives 3 through 6, a Research and Development (R&D) Model was implemented (see Figure 1). As seen from the figure, there are two main stages in the R&D cycle: formative and summative. The purpose of the formative stages is to gather data which will facilitate program improvement. During the summative stage, data which are related to program effectiveness are collected, (i.e., data which describe the performance characteristics of the product).

## Formative Evaluation

During the planning stage of the R&D cycle, a needs assessment is conducted. The data from the needs assessment provide the basis for identifying curriculum content.

In 1977 a needs assessment was conducted in a northern Utah county; fifty adult developmentally disabled persons were involved. A Camelot Behavior Checklist (Foster, 1974) was used to assess the degree to which the fifty AADD persons had acquired daily living skills. The data from the needs assessment were as follows.

1) More than 80% of the sample surveyed indicated deficiency in:
    - a) car maintenance (96%); and
    - b) proper credit use (96%).
2) From 60% to 80% of the sample surveyed indicated deficiency in:
    - a) personal security (79%);
    - b) money handling (75%);
    - c) shopping (75%);
    - d) arithmetic (68%);
    - e) responds appropriately to emergencies (68%);
    - f) appliance use (64%);
    - g) balanced diet (61%); and
    - h) cooking (61%);
3) From 40% to 60% of the sample surveyed indicated deficiency in:
    - a) basic writing skills (57%);
    - b) initiates own leisure time activity (54%);
    - c) interacts with others (54%);
    - d) social and legal responsibility (54%);

e) telephone skills (54%);
f) basic reading skills (46%);
g) transportation (46%);
h) various job skills (46%);
i) yard care (46%);
j) health care (43%); and
k) participates in various activites (43%).

Having identified skill deficits, the trainer has to decide how best to overcome them. There are two options available: implement existing packages and/or develop new ones. A review of presently available materials indicated that validated packages were available in the areas of: (1) personal security; (2) health care; and ([illegible] response to emergencies. Therefore, it was necessary to develop and validate packages in those areas of critical need for which no packages were available. These included: (1) proper credit use; (2) diet and nutrition; (3) appliance use; (4) housekeeping; and (5) cooking.

Each content area was task analyzed (i.e., broken down into smaller instructional steps). A packaging prototype was then developed to teach each instructional step. As has been mentioned, it was critical that the instruction be designed in such a manner as to enable a paraprofessional to implement the program with a minimal amount of training. To accomplish this, a direct instruction format was implemented. That is, everything the teacher was to say and do was clearly spelled out. (An example of the format appears in Figure 2.)

Once developed, each prototype was submitted to a group of experts who were asked to review the program with reference to the appropriateness of its content and format. Revisions were then made, based upon the feedback from the critique.

Upon revising the prototype, the instructional programmer implemented the prototype with a small number (one to five) of learners. The purpose of this phase was to gain feedback regarding the clarity of the instructions, the appropriateness of the sequence, and the effectiveness of practice.

Using the data from the initial field test, the programmer revised the prototype.

At present, each prototype is in the volunteer field-test stage. The purpose of this stage is to determine if the programs can be effectively implemented by those who will eventually use the programs, (i.e., paraprofessionals). In addition to gathering learner performance data, the project staff is also gathering data on ten volunteer's reactions regarding (a) the clarity of the instructions, (b) the format, and (c) the usefulness of the materials. Also, volunteers have been asked to record any particular problems encountered while teaching the program.

The volunteers are implementing the programs in a variety of settings, including private homes, group homes, nursing homes, and sheltered workshops. Prior to implementing the programs, each group of volunteers received a brief training session on using the instructional packages as well as recording data.

Upon completion of the volunteer field-test, each prototype will undergo yet another revision. Revisions will be made on the basis of the data collected during the field-test. Should any prototype require further revisions, it will be "recycled" through another volunteer field-test prior to entering the summative evaluation stage.

Summative Evaluation

Once the prototypes have successfully completed the volunteer field-test stage, a final field-test will be conducted to assess the effectiveness of each program under more rigorously controlled (i.e., experimental) conditions. In addition to evaluating the effectiveness of the instruction, the functional utility of delivery system (i.e., implementing self-contained packages in a variety of situations) will also be assessed.

Revisions in format, based upon the summative data, will be made prior to final dissemination.

When the programs have been validated, they will be disseminated through the Outreach and Development Division of the Exceptional Child Center. The Division disseminates validated instructional materials, at cost, both nationally and internationally.

## Future Implications

The utilization of a Research and Development approach to attack the educational problems of the AADD has several implications for the future. The programs developed in the R&D process will be in a highly replicable format, increasing the potential for assessing their generalizability. Each program can be tested across the country under a multitude of conditions.

In addition to meeting the educational needs of the AADD, the instructional programs will also help meet the training needs of the paraprofessional supervisors of the AADD. Few of these persons presently possess effective teaching skills. This situation is best remedied by having the paraprofessional supervisor implement validated instructional materials, rather than attempting to train them in global teaching skills, with the hope that the paraprofessional supervisor will generalize such skills to the actual teaching situation. By utilizing direct instructional materials, the supervisor models (and thus learns) effective instructional techniques and simultaneously teaches a critical skill to the handicapped adult.

The implementation of the research and development process will involve a considerable initial commitment of manpower and resources. When one considers the potential for impact, (i.e., the national dissemination of validated instruction which can be readily implemented by paraprofessionals), with literally thousands of handicapped persons, the benefits far outweigh the costs.

One must also consider the costs of no systematic instructional intervention. The movement towards normalization has resulted in the placement of AADD persons in a variety of community settings, with the assumption that such placements were more humane than continued institutionalization. As our needs assessment data, and the data reported by others (Kriger, 1975; Nihira and Nihira, 1975b) indicate, the AADD have been ill prepared for adapting to these placements. Further, as a result of collecting skill data and reviewing the literature, our observation suggests that few systematic attempts have been made to remedy the problem. Given the technology and financial resources available (e.g., Title XX), to allow these behavioral deficits to continue constitutes neither normal nor humane treatment.

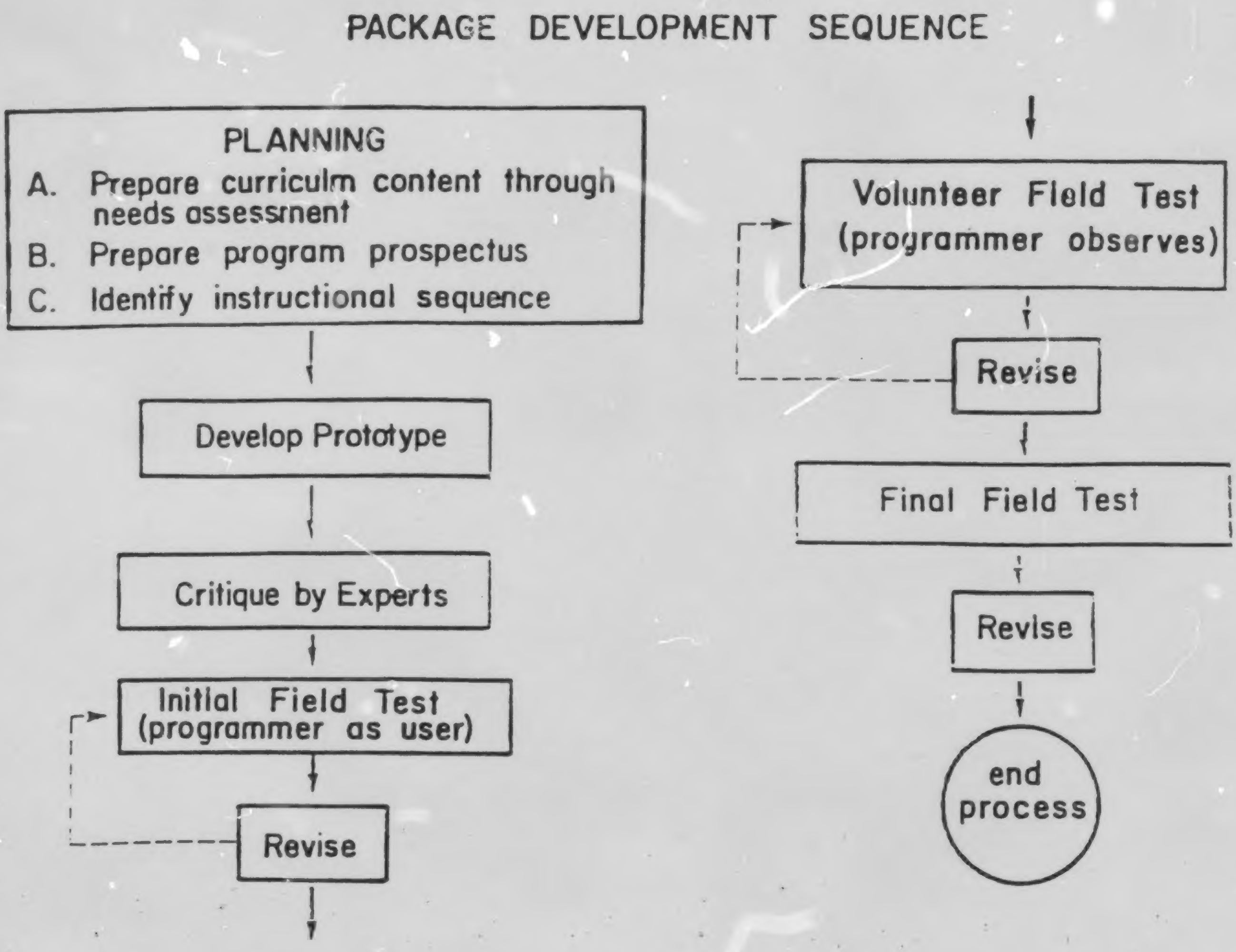
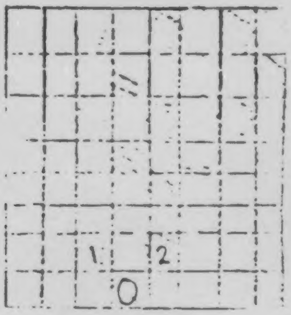

PACKAGE DEVELOPMENT SEQUENCE
PLANNING
A. Prepare curriculm content through needs assessment
B. Prepare program prospectus
C. Identify instructional sequence
Develop Prototype
Critique by Experts
Initial Field Test (programmer as user)
Revise
Volunteer Field Test (programmer observes)
Revise
Final Field Test
Revise
end process

Figure 1: Package Development Sequence

## LESSON 2: MOVING A CHECKER TO AN "EMPTY" SQUARE

I. (Set up Learner's checkerboard as shown in diagram.)



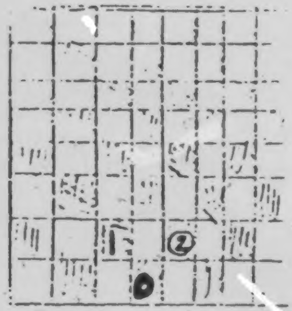
I. (point to square numbered 1

IF THIS SQUARE IS EMPTY, YOU CAN MOVE YOUR CHECKER THERE.

(Point to square numbered 2

IF THIS SQUARE IS EMPTY, YOU CAN MOVE YOUR CHECKER THERE.

(Place a checker on square numbered 2 so checkerboard looks like this)



I. (Point to square numbered 1)

LOOK.

IS THIS SQUARE EMPTY?

L. Yes.

FIGURE 2: SAMPLE PROGRAM FROM A PAGE IN THE PROGRAM TEACHING A GAME OF CHECKERS

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# A REPORT OF A STUDY OF A NEEDS ASSESSMENT OF THE ADULT AND OLDER DEVELOPMENTALLY DISABLED PERSON AND ITS IMPLICATION FOR SERVICE DELIVERY

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## Introduction

Before discussing the project I coordinated at Temple University Rehabilitation Research and Training Center in Philadelphia concerning the service delivery system for substantially handicapped developmentally disabled adults (Gordon, 1977), I would like to take this opportunity to reiterate that which you have already discovered for yourselves. The deveopmentally disabled adult is beginning to emerge from what Dickerson et al. (1974) termed the "cloak of invisibility." If they are not as yet a well defined serviceable entity, at least they have become a growing group of individuals who collectively are challenging the consciences of those developmental disabilities service providers and program planners who are becoming aware that service is not synonymous with cure.

For example, I am sure that few people involved in the field of developmental disabilities, regardless of professional background or education, would expect that the primary conditions of mental retardation (impaired intellectual and socio-adaptive functioning), cerebral palsy (brain damage affecting the motor system), epilepsy (brain dysfunction resulting in convulsions), or early infantile autism (a psychotic disturbance thought to be related to as yet incompletely understood organic and/or genetic factors) are "curable" disorders. While each specific disorder may have associated with it needs for specialized medical and allied health services, all of these developmental disabilities eventually become the focus of special educational programming. However, when the child grows into adulthood and is "graduated" from school, he no longer exists as a member of a significant consumer group requiring specialized services. At least this is a conclusion you must reach if you look at the current delivery system of services available to the developmentally disabled adult. It is as if he has been cured of his primary problem and is now expected to be treated generically as part of a group of similarly aged peers. If significant problems persist, he is either closeted by the family or institutionalized.

The implications for the developmentally disabled aged are enormous. I will attempt to demonstrate by combining inference with empirical evidence that the neglected specialized needs of young developmental disabled persons have a direct bearing on the needs of older developmentally disabled persons, and that the inadequacies of the service delivery system to meet these needs factorially expand in later adulthood. The cummulative result is the exacerbation or quickening of the aging process, at least with respect to the social dependency, isolation, and, to some degree, physiological deterioration of the developmentally disabled adult.

I would like now to briefly describe the study, entitled "A Study of the Medical and Allied Health Service Delivery System for the Substantially Handicapped Developmentally Disabled Adult," its objectives, methods, results and some of its conclusions. I will also briefly discuss a sibling study (Hamilton, 1977), performed at the Northwestern University Rehabilitation Institute of Chicago, and then attempt to draw implications from these studies for the agining developmentally disabled adult.

Purpose and Goals of the Study

The 1970 Developmental Disabilities Act (Public Law 91-517) gave impetus to the official recognition and sanction of a multidisciplinary approach needed for the prevention, early identification, and management of disabilities associated with a host of childhood problems which serve to significantly and chronicallly debilitate handicapped individuals. Developmental disabilities are disabilities which orginate early in life (before the age of 18) and persist throughout the life span. The early incidence and permanence of a developmental disability produce an impact on the on the individual and family that is greater than the vicissitudes of typical development, or of disability which originates in adult life (Battle, 1974; Farber, 1975; Wolfensberger and Menolascino, 1970).

While the definition of developmental disabilities as most recently revised by Public Law 94-103 (1975) enlarged the specific categories of disabilities to be included, the main intent of DD remains constant. Essentially, it is an administrative concept (Stedman, 1974), the utility of which is a broadnet focusing on the problems common to those substantially disabled in early life. One of the major problems of this population is the frequency of multiple handicapping conditions which often serve to exclude the very individual most in need of special services. Another problem is the lack of integrated service delivery programs to meet the multiple needs of a developmentally disabled person such that fragmented services exist due to statutory constraints, isolated or restrictive perspectives of the service providers, and disorganization or lack of transitory support services. Also, since by definition developmental disability refers to lifelong duration of handicapping conditions begun in childhood, there exists a discontinuity of services to substantially handicapped children as they age, either as a result of their reaching arbitrary age limits or when the individual developmentally disabled person is considered to have reached maximum benefit (Mesner, 1969). Thus the Developmental Disabilities Act of 1970 represents an attempt to provide an administrative approach to help program planners and service providers to make available appropriate services to those children and adults who, because of the multiplicity and severity of problems, require a systematic service delivery program for the duration of their lives.

In order that a comprehensive plan for the total array of services needed by this segment of our population be implemented, it appeared essential that descriptive data be accumulated about the problems, service needs, and current service availability to the developmentally disabled person. Gaps between service needs and availability were to be identified as well as those problems which rendered the service delivery system ineffective.

Thus, Social and Rehabilitation Services of HEW funded two studies of national significance in order to determine the characteristics of the existing medical and allied health services delivery system in two separate geographic areas, Illinois and Pennsylvania, for substantially handicapped developmentally disabled adults, and to delineate a feasible methodology for determining the current needs of this segment of the population and those of the present delivery system to meet those needs. The Illinois study focused on the urban area of Chicago, while the Pennsylvania study included metropolitan Philadelphia as well as a rural area of northeastern Pennsylvania. There was a similariity of approaches used by both studies (with some important differences which will be discussed later), which produced similar findings and made the resulting data concerning the samples studied more useful than originally expected.

Methodology

In the Pennsylvania study, 119 subjects were selected from two specific subpopulations of substantially handicapped adults, all of whom were known to a service agency, who were 16 years of age or older. and whose legal residence was in either an urban or rural Pennsylvania county. Each subject was individually evaluated by each member of a diagnostic team of experienced medical and allied health professionals (physicians, physical therapists, occupational therapists, speech and hearing specialists, dentists, social workers and psychologists). The evaluation of each subject lasted for approximately 10 hours, and was followed by an interdisciplinary team conference to determine the current and future service needs associated with each subject's identified medical and allied health problems, as well as to collectively prioritize in hierarchical fashion these service needs. A second professional team (Critical Survey Team) surveyed the existing urban and rural medical and allied health service delivery systems from which the developmentally disabled subjects were selected and critically evaluated these systems' characteristics and limitations.

Subject Selection and Disability Categories. The primary intent of the 1970 Developmental Disabilities Act was to provide services to those persons who, because of their multiple handicaps were being excluded from obtaining services through the service delivery system. Thus, substantially handicapped adults were defined broadly in this study to refer to developmentally disabled persons who had some physical and/or mental disability of such generalized severity as to need not only one service (such as special education) but rather multiple services over an extended period of time. This was a comprehensive definition involving many interacting variables which had to be taken into consideration if a realistic assessment of the needs of substantially handicapped, developmentally disabled adults and the delivery system servicing those persons was to be made. Such variables included, among others: the number and type of disabilities; the degree of severity of intellectual impairment; the age, sex and socioeconomic condition of the person; and the environmental (community-familial) support systems available to the person; and the support systems available to the group of persons sharing a common type of developmental disorder (for example, such support systems as national and local organizations which provide diagnostic and treatment services and referrals, politico-legal support, etc.).

Because of the heterogeneity of the population, the limitations inherent in a pilot study of such brief duration, and because of the desire to obtain useful results in terms of the general and more broadly defined goals, this investigation selected two samples of developmental disabilities which could be compared directly in terms of some of the diverse and interacting variables mentioned above.

Mentally retarded individuals were used because one of the major impacts on the rehabilitation process is the level of intellectual functioning which is often associated with known and subtle neurological impairments. Thus, the two samples which were selected and which conformed to the broadly defined criteria for substantially handicapped developmentally disabled adults were: cerebral palsy concomitant with mental retardation an epilepsy concomitant with mental retardation. It should be pointed out that by selecting these subjects according to their disabilities all three of the primary categories of developmental disabilities as defined in the 1970 Developmental Disabilities Act were included. There were 63 cerebral palsied mentally retarded subjects (52.9% of the total sample) and 56 epileptic mentally retarded subjects (47.1%) included in the sample.

Geographic Location. Because of the different service delivery system characteristics expected between urban and rural areas, and the impact these differences may have on current and furture service needs, the subjects were selectedd from Philadelphia County (urban) and Wayne County (rural). Eighty subjects (67.2%) were selected from the urban area while 39 (32.8%) had their legal residences in the rural area. Thirty-seven subjects (31.1%) were residing in institutional facilities, 23 urban (28.8%) and 14 (35.9%) rural. However, all subjects were at one time part of the Philadelphia or Wayne County service delivery system by the nature of their legal residences or those of their families.

Age. Adults in this study were defined as being 16 years of age and older, which was more related to the rehabilitation process and the end of schooling than to reaching age majority. In an attempt to determine, indirectly, the impact the increased federal and state attention, legislation, and programs, had on this population since the 1960's, it was decided to use the age groups 16 through 20 and 26 through 40, thus providing a 20-year span for comparison purposes. These age criteria had to relaxed in order to fill the intended subject sizes. Thus, a young group (16-25 years) and old group (greater than 25 years) were constituted. For the purposes of this conference on the aged developmentally disabled person, the age of the "old" group is somewhat young to be referred to as the aged; and, really, I have no intention to do so. However, as I will attempt to demonstrate, the large gap between need and service delivery of even this relatively young group can be expected to compound later service needs. The mean age for the entire subject group was 25.5 years (reflecting the initial selection bias) and ranged from 16 years to 46 years of age. Seventy-three subjects (61.3%) were classified as young, while 46 subjects (38.7%) were classified as old.

Other selection criteria. With the exception that all subjects had to be known to the service delivery system, i.e., currently receiving some service, no other criteria were used to select the subjects. However, a number of other demographic characteristics were obtained and described in the final report, including: sex, socioeconomic status, race, religious preference, marital status, current employment status, source of financial support, medical insurance, parents' marital status, and current living arrangements.

Critical Survey Team. An exhaustive search of developmental disabilities service providers was performed by the Critical Survey Team in an attempt to gain a broadbased data bank of the general characteristics of the urban service delivery system. Additionally, the search was to provide the basis for subject referral to the Diagnostic Team's interdisciplinary examinations. Initially, the agencies were contacted via mailed questionnaires requesting the following information: type of facility, type of services provided to the general population as well as to the developmentally disabled, number and type of disabled person served, eligibility criteria, sources of revenue, other facilities which served developmentally disabled persons, and willingness to participate further in the study. From the returned questionnaires, 148 agencies were identified as serving the developmentally disabled population in and around Philadelphia. In the second phase of the agency survey, 25 facilities were identified as providing services to developmentally disabled adults, and 18 were visited by the Critical Survey Team for an in-depth, on-site interview. An interview schedule was developed and piloted and, in its final form, covered the following areas in detail: (1) service center characteristics (population served and agency characteristics); (2) range and type of services provided; (3) eligibility criteria, admission procedure, and source of referral; (4) outreach program; (5) record-keeping and information exchange; (6) manpower needs and staffing levels; (7) linkages and care network; (8) financial arrangements; and (9) goal structure of the service agency. A similar interview schedule was developed for the rural service agencies, and each of the 10 identified agencies serving the developmentally disabled adult population was interviewed by telephone conference calls.

Limitations of the Methodology. There are several major factors which serve to limit the generalizability of the findings: (1) sample size, (2) selection procedure, (3) definition of quality of care, (4) importance of certain services over others, (5) access to service agencies, and (6) the availability and compatability of requested information.

The subject sample size was rather small. However, the available clientele who precisely fit the selection criteria was nearly exhausted. Therefore, the data very well may represent the service needs of substantially and multiply handicapped developmentally disabled adults. Also, all subjects were already known to the service delivery system and were being provided some service. The service needs of those persons who were unknown to the system can only be surmised. Thus, the current findings should be viewed as minimal requirements of a comprehensive, integrated service delivery system to this population.

Quality of care can be defined in a number of ways in needs assessment surveys of the kind involved in this study. While the type and number of services which were needed and their availability were quantified, due to time and financial constraints no attempt was made to assess the adequacy or effectiveness of the services which were then being delivered to the subjects. Another study focusing on the effectiveness and adequacy of services rendered, taking into consideration the present state-of-the-art of the [illegible]ious medical and allied health disciplines, is needed to ascertain the quality of care currently available to developmentally disabled persons. It should be noted, however, that the present study represented what may have been the first of its kind by objectively and directly determining the needs of the consumer as well as the gaps in the service delivery system. Most studies survey the views of agencies as to their clients' needs and/or ask the client to specify his needs and problems. This study used an interdisciplinary team, the members of which were not part of the service agencies, to evaluate client needs and service availability.

While all the service needs for each subject were prioritized in hierarchical fashion, the summary of the total sample's needs and gaps in service delivery did not delineate the importance of one service over another. Some services are clearly more important than others. For example, some services are so necessary as to be considered life-saving; others are needed to maintain the current level of functioning; still others relate to improving the quality of life of the person. Also, some services are necessary precursors for others (like transportation). All the services assessed in the study were treated as equal units in order to describe objectively the system as a whole.

Finally, the agency survey was limited in the willingness of or lack of incentives for agencies to participate. This was more true of urban than rural agencies. A larger agency sample size would have resulted in greater confidence of the findings. In the same vein, many agencies (particularly the rural ones) do not keep adequate records, and even when they do, they rarely were in a form compatible with other agencies and/or the survey questionnaire. Site visits were performed, but the information in many cases was estimated.

## Results

The findings from the medical and allied health examinations are extensively documented within the study's final report. What is more relevant for this conference is a summary of service needs which were based on the interdisciplinary diagnostic team's findings, and on the critical survey team's analysis of the service delivery system.

Evaluations of the study's sample of multiply handicapped developmentally disabled persons revealed that only 22% of their medical and allied health service needs are being met by the existing delivery system. Living in a major urban area rich in professional resources and training facilities is an advantage in terms of receiving needed services compared to residing in a rural location. However, a 75% gap in services rendered to urban developmentally disabled persons as opposed to an 84% service gap for rural developmentally disabled persons can scarecely be considered adequate. Incidentally, 80% of the cerebral palsied and 75.6% of the epileptic mentally retarded persons' needs are unmet.

The average number of total service needs, current and future, for our entire sample was 23. An average of 4 needed services are now being provided by the system, whereas an average of approximately 15 new service needs were recommended in order to provide adequate care. If these figures appear high, it may be related to the nature of the examinations; the evaluations were more intensive and more comprehensive than most that are available in a clinical setting. Thus, what may appear to some as over-estimations of service need may be a more accurate reflection of the actual service needs for this population. While some specific differences were identified in the types of medical and allied health problems observed, services recommended, and gaps in service delivery discovered, generally the total array of problems and amount of services needed did not significantly differ according to disability category or geographic location.

Essentially, the results of this study support the contention that multiply handicapped developmentally disabled persons constitute a group of people with problems of differing specific etiologies requiring similar long-term services of a lifelong and multidimensional nature. The large disparity between service needs and service delivery as revealed in this study, especially for those who could not afford the costs of seeking private services to fill the service gaps, contributes significant verification for the usefulness of the broad concept, "developmental disabilities."

Another inescapable finding from this study relates to the age range of the sample used. All subjects were considered adults, 16 years or older. It was expected that the growth in service availability, increased technology in treatment and training, and greater federal, state, and local mandates over the past 15 to 20 years would have had an ameliorating impact on current service needs of the younger adults (16 to 25 years of age) compared to the older adults (26 to 46 years of age) in our study. No such trend was observed; both groups seemed to have difficulty receiving needed services. Whether there has been no impact in an absolute sense or whether there has been an impact which could not be observed through the design of this study, is unclear. Regardless, the considerable service needs and gaps in service delivery to those developmentally disabled adults mitigate against the popular notion that the adults' medical and allied health service needs are simpler, fewer, and/or less acute than younger, developmentally disabled children. It appears reasonable, and consistent with the federal definition of developmental disabilities, that the handicaps in this population are substantial and lifelong in duration. The discontinuity between services to developmentally disabled children and adults appears arbitrarily imposed rather than realistically based, and most likely relates to the needs of the system and not to the people for whom the system presumably operates. What is needed for both comprehensive service delivery and planning is a life planning program (Gordon, 1975) which begins when the disability is first diagnosed and continues into adulthood for the life of the developmentally disabled person. This life planning program would be based on a periodic functional evaluation performed by an interdisciplinary team of professionals especially trained in all aspects of developmental disabilities. As the developmentally disabled person moves from one life stage or one aspect of the service delivery system to another, his current functional needs can be assessed and an appropriate, integrated service plan devised and implemented.

The aspect of this study relating to the urban and rural service delivery systems for developmentally disabled persons has led to a number of conclusions concerning the strengths and weaknesses of those systems. The data generated from the two agency interviews, along with the data from the client evaluations point to the need for new and expanded services in a wide range of service categories as well as to the need for new techniques in manpower training and program evaluation

Several problems are reducing the efficiency of the urban service delivery system as it now exists. Primary among these problems has been the difficulty in establishing sufficient interagency linkages to enable any overall program coordination. Although the Base Service Units in each catchment area are legally mandated to provide evaluation, information and referral to all persons within their area, the multiplicity of points of entry into the service system makes it virtually certain that many persons will entirely bypass the Base Service Unit when they obtain service. It is theoretically possible that all persons receiving service will be known to the Base Service Unit, which could then supply the overall coordination for the services they were receiving. But it is equally possible that many persons will never be known to the Base Service Units, or that they will at some point "fall out" of the system and return to the community without receiving adequate follow-along. Our patient data, which found a 50% service gap in the area of Base Service Unit follow-along, seems to suggest that this is the more likely possibility. If the follow-along services of the Base Service Units became more effective, they would be the most logical centers for providing the life planning programs previously described.

Compounding the problem of multiple points of entry into the system is the fact that agencies are further isolated by the multiple, and sometimes overlapping or competing, streams of funding. All three levels of government--federal, state and local--are providing funding to both the community mental health/mental retardation system and to the specialized agencies and associations which supplement the system. In many cases funding which bypasses the MH/MR system might well have been used to enhance existing programs if coordinated planning had been utilized. Also, the lack of coordination sometimes results in the failure of agencies to apply for funding for which they are eligible. This suggests the need to clarify and streamline existing funding mechanisms if the maximum benefits are to be derived from allocation for developmental disabilities services.

There are several specific suggestions, both in terms of administrative procedures and services needed, which can be made on the basis of the agency analysis. A priority item which should be thoroughly studied is the feasibility of implementing a statewide data collection system to monitor the patient flow and service delivery of all agencies providing service to the developmentally disabled person. Such a system would facilitate evaluation management and planning for both the State Councils on Developmental Disabilities and for individual agencies. It is encouraging that such a data collection system was mentioned in the Pennsylvania Annual Revision of the Developmental Disabilities State Plan, particularly in view of the poor record management, record keeping, and information transfer which was found to be prevalent among the agencies included in both the Initial Interview Sample and in the In-Depth Follow-Up Interview.

Our agency analyses found that a low priority and emphasis was placed on outreach. Given the fact that nearly 50% of the estimated total of developmentally disabled persons in the Philadelphia area were not known to the system, it would seem advisable to conduct more extensive outreach efforts. Based on the nature of the current referral network, these efforts could include public education and awareness programs, efforts to contact hospitals, private physicans, schools an other agencies, and media campaigns. However, these efforts will be effective only to the extent that additional funding and manpower are made available to carry them out.

In conjunction with expanded outreach programs, an increase in the availability of a wide range of services must also be initiated. The agency analysis indicated significant service gaps in the areas of medical services (including physical diagnosis, physical therapy, speech therapy, occupational therapy, and dental services), general services (including transportation, casework counseling and recreation), mental health services, educational and vocational services, and special living arrangements. These services must be expanded, not only to provide more comprehensive service to those persons already within the system, but also to accomodate the additional need which would be generated by increased outreach efforts.

A problem associated with the need for new and expanded services is the need for new professional training programs specifically focused on the needs of the developmentally disabled. Over half of the respondents in our agency Follow-Up Interview (53%) felt that there was a need to develop new careers in the area of developmental disabilities, and 76% of the agencies felt that the current professional training was only fair or poor. These new careers must incorporate an interdisciplinary approach based on the broad, functional needs of clients rather than on the generic classification of disabilities.

The study of the rural service delivery system has indicated a wide range of unfilled needs, and has led to a number of conclusions regarding the major barriers to improved service for developmentally disabled persons in this area.

There are service gaps in virtually every category of service. Among the areas of greatest unfilled need are special medical services (such as physical therapy), transportation, special living arrangements, and vocational and training services. However, simply identifying the areas of need does not fill the service gaps. There are several major obstacles to the provision of service to developmentally disabled persons in this area. Chief among these is the problem of transportation. This is a problem for the general poulation as well as for the developmentally disabled persons in this area. However, the problem of transportation is the most acute. It is manifested not only in the lack of transportation facilities, but also in the long distances separating many services, especially in the rural areas. Lengthy rides to and from service agencies undoubtedly discourage some persons from utilizing services even when transportation is available. For this reason, transportation is a much greater problem in rural areas than in urban areas.

A second major barrier to the provision of service is the lack of facilities. This is associated with the transportation problem and could be partially ameliorated in two ways. Mobile units could provide services such as physical therapy and other special medical services, eliminating the need for additional permanent therapy and other special medical facilities. The Community Mental Health/Mental Retardation Center is using this technique by employing a roving Outreach Worker who provides supportive counseling and referral to the developmentally disabled and their families in their own homes. A second technique is to establish small group homes near major facilities such as vocational workshops, thus eliminating the need to travel. This is expensive, however, and still does not eliminate the problem of reaching other services and facilities. The best solution is probably a combination of both techniques--both increased special living arrangements near training and rehabilitation facilities, and better utilization of existing manpower resources.

The existing community biases and lack of long-range planning also pose serious obstacles to improved service for developmentally disabled persons in rural areas. The local bias against developmental disabilities is much stronger than in urban areas. This inhibits many individuals and families from seeking help. Increased community education efforts are needed to raise the level of community awareness and understanding of the problems and potentials of the developmentally disabled person. Along with this increased awareness and understanding must come better planning for long-range needs and goals. A complaint of several of the respondents to the Rural Interview Schedule was that there was too little planning and overall program coordination. Too often agencies are operating in a void, and often at cross purposes to each other. The expanded role of the Community MH/MR Centers in this rural area may help to reduce this problem.

While the problems of the rural service network are considerable, and the obstacles to any improvement are very real, there are also some definite strengths to the system. It seems to be unlikely that people will "get lost" or "fall out" of the care network once they have made contact, if only because the system is much smaller and less complicated than would be found in a major urban area. In summary, much improvement is needed in nearly every aspect of the service and planning. Much of this will take increased money and manpower, both of which are usually in short supply. But the very fact that an initial assessment of the situation has been made makes the situation a stronger one for future planners.

The general goal of all of these recommendations is to increase the number of persons being served and to improve the quality and range of services which they receive. There is no single panacea which will realize these goals. The planning and evaluation activities of the State Councils have provided a major impetus towards the improvement of service in the area of developmental disabilities. Better interagency coordination can only help to improve services. A continuing necessity is to maintain the awareness that service gaps do exist, linkages between agencies are often inadequate, and that current funding and administrative procedures often complicate the situation. The state, as the dominant funding source, must continue through the State Council to take the lead in initiating and coordinating the changes necessary for the improvement of the overall Service Delivery System.

## The Chicago Study

The research efforts of the Temple University Rehabilitation Research and Training Center in Philadelphia and those of the Northwestern University Rehabilitation Institute of Chicago were the results of extensive collaboration between the two facilities. Thus, the goals were identical; the general methods were the same, although some of the specifics were intentionally varied; and the findings overlapped substantially, thereby providing not only cross-validation but also permitting generalizable conclusions.

The Chicago study selected its subject sample differently than did the Philadelphia study. However, once the subjects were selected, they were provided extensive multidisciplinary evaluations from which medical, allied health, and social problems were identified. These problems were further assesed as to their resolvability, both in the past, assuming that the subject had been exposed to appropriate services, and in the present. Further, the list of problems formed the basis of the service needs of the sample. Also, like the Philadelphia study, the Chicago study made an independent service delivery system analysis for developmentally disabled adults in the Chicago metropolitan area. The Philadelphia study was a comparative investigation focusing on (1) urban vs. rural service delivery systems; (2) the contrasts in health and social problems among segments of the developmentally disabled population (cerebral palsy vs. epileptic mentally retarded persons, young vs. old developmentally disabled adults, low vs. middle/high socio-ecconomic status groups, levels of mental retardation); and (3) current and future prioritized service needs as identified by an interdisciplinary team. The Chicago study was a demographic study emphasizing (1) a broad sampling of the entire range of developmentally disabling conditions within a large metropolitan urban area; (2) the modifiability of health and social problems identified by a multidisciplinary team; and (3) a comprehensive analysis of an urban service delivery system.

Rather than having service providers identify the developmentally disabled subjects who would be eligible for the medical and allied health examinations, the Chicago study attempted to identify those developmentally disabled persons who may not have been a part of the developmental disabilities service delivery system. Through the method of public media announcements, an estimated 2% (3,800 persons) of the potential developmentally disabled consumers in Chicago were identified. This self-identified group was sent questionnaires producing 696 responses (18%) of which 625 met the criteria for classification as developmentally disabled adults. From this group of 625, 124 were selected on a partially random basis for the multidisciplinary medical and allied health examinations, and an additional sample of 78 developmentally disabled persons consented to having their past medical records reviewed as a validation procedure.

In terms of identifying agency providers to the developmentally disabled population in Chicago, an extensive questionnaire mailing was done covering the same informational areas as the initial questionnaire sent out by Philadelphia. Six hundred and seventeen agencies characterized themselves as developmental disabilities providers from which 55 were selected on a random stratified basis for in-depth, on-site interviews.

The 124 subjects who were clinically evaluated by the Chicago team were distributed among the following developmental disabilities categories: 40% cerebral palsy-mental retardation; 27% mental retardation; 15% cerebral palsy; 8% epilepsy; 2% cerebral palsy-epilepsy. The mean age of the subjects was 30 years, the range was 15-74, and the majority were young adults (75% were 34-years-of-age or younger). As it was pointed out in the study, the skewed distribution within the younger age category (16-34 years) was nearly double the proportion in the population at large. No subject was currently residing in an institution due to the nature of the self-selection method of sampling. Fifty-one percent of the sample was male, and 49% female. Only 12% of the sample was black, which was less than half the expected proportion in the population (28%).

The findings from the Chicago study were similar to those found in the Philadelphia study in terms of the number and types of health and social problems identified, services needed, and gaps in service delivery. The clinical evaluation team identified 1,346 problems (an average of 10.9 problems per subject), 70% of which were categorized as physiological, and 30% socio-environmental. The greatest frequency of problems occurred in the most multiply handicapped group (cerebral palsy, mental retardation, and epilepsy combined--an average of 21 problems per subject); the least occurred in the group with epilepsy alone (7 problems). The combination of cerebral palsy and mental retardation averaged more problems (15) than with either alone (13 problems each). Additionally, it was found that of the existing problems in the sample of developmentally disabled adults, 62% were considered treatable today and 87% would have been treatable in childhood by current standards of care. ("Treatable" refers to the expectation that had service been provided, the current problem would have been improved, but not necessarily eradicted.) Most importantly, the Chicago study determined that of the existing identified problems, 42% could have been prevented or improved to the point where current treatment would not be necessary.

High among the unmet service needs identified in Chicago were: (1) transportation, (2) vocational training and placement, (3) financial aid, (4) residential placement, (5) information/referral, and (6) education. Additional unmet needs which were also identified in Chicago but which ranked somewhat higher in Philadelphia were medical, dental, speech, psychological, recreational, and day-care services (as well as the ones identified in Chicago with the exception of residential placement needs). These slight differences between the two studies most likely reflect differences in the sample selection process, the degree of existing multiple handicaps in the samples used, and the nature in which the clinical teams functioned (multidisciplinary vs. interdisciplinary orientation). However, the tremendous overlap of the findings from the two studies, particularly in view of the metholological differences, clearly support the inadequacy of the current service delivery system to provide for the health and social needs of the developmentally disabled adults.

Chicago's analysis of the problems of the system of service delivery to developmentally disabled adults led to the following recommendations:

1. Develop a service delivery model based on a problem-solving concept and consisting of the elements of awareness (of patient/client problems and source of solutions--services--by both consumers and providers), availability of services for solving the problems, appropriate accessibility by the consumer for services, determination of effectiveness of the provided services with the participation of the consumer, and overall coordination of

the service system directed at maximizing problem-solving capability at least cost.

2. Increase awareness of service availability by continually updating and widely disseminating a registry of services in the community specifically for the developmentally disabled.
3. Provide trained coordinators of developmental disabilities services who are multidisciplined, readily identifiable, and easily located.
4. Publish and disseminate information regarding alternative sources and procedures for obtaining developmental disabilities service funding.
5. Reduce transportation and architectural barriers for the mobility-limited through enforcement of existing legislation, reduce costs for transportation, and provide more accessible vehicles and routes.
6. Provide earlier, appropriate vocational training for the developmentally disabled person.
7. Provide better service follow-up and evaluation of service outcome.

## Implications for Aged Developmentally Disabled Persons

Dickerson et al. (1974) discussed the double jeopardy of being both old and developmentally disabled, and indicated that the aged developmentally disabled person is an invisible client so far as the literature and service delivery system are concerned. Based on the findings of the two studies just described, several logical conclusions can be offered which pertain directly to older developmentally disabled persons.

1. The older developmentally disabled adult is difficult to locate. Of those developmentally disabled adults who responded to the Chicago study's media campaign, three-quarters were in the young adult category (ages 16 to 34), which was nearly double the proportion in the population-at-large. Only 12% of the developmentally disabled adults responding were older than age 44, which was one-quarter of the total population for this age group. According to the 1970 United States Census, Philadelphia had a greater proporation of young persons (19 years and younger) and fewer older persons (45 years and older) than both Chicago and the nation. Nevertheless, the Philadelphia developmental disabilities agency survey showed even larger proportions of young disabled people and under-representation of older disabled people than is seen in the Philadelphia census data (42.5% aged 25 or younger, 20.8% over the age of 40). The reasons for these skewed distributions toward the younger disabled adult are not likely related to the higher rate of institutionalization which is expected with increasing age. While Chicago did not include institutional facilities in their evaluations and surveys, Philadelphia did, and the trends for younger developmentally disabled adults to be known and serviced by the delivery system were relatively consistent between the two studies. Quite possibly the under-representation of old people and the preponderance of younger persons in the sample populations are due to the shorter life spans common among many developmentally disabled persons. That there simply are fewer older developmentally disabled persons around, given our advanced medical technology and knowledge, would only emphasize the discrepancy between current quality care capability and its unavailability to this seg-

ment of our population. The impact this discrepancy has on the physiological status of the developmentally disabled will be discussed shortly. A final explanation is that the guardians and other caretakers responsible for older developmentally disabled persons simply do not avail themselves of the existing services as frequently as do the guardians of younger developmentally disabled persons. Loss of hope in the system to provide adequately for their charges, transportation problems, lack of awareness of where to find appropriate services, health problems of the aging guardians, and/or social stigmata probably contribute to the guardians' no longer seeking the services. Extensive outreach programs were recommended by both studies to overcome this problem of locating developmentally disabled adults, and there is a need for more complete follow-along and information/referral services to provide a coordinated continuation of service delivery as the developmentally disabled adult's needs change.

2. Developmentally disabled persons "age" more rapidly than the general population and they do so as a result of inadequate service delivery. Physiological changes are a part of the aging process which all of us will experience as we get older. However, many of the health problems identified by both the Philadelphia and Chicago studies in relatively young adults can be considered premature by typical aging standards. For example, dental problems usually occur in older persons; however, the dental examinations of developmentally disabled adults (in the Philadelphia study, oldest age was 46 years) revealed that dental services were the second highest ranked of all medical service needs (first, in Chicago), and

yet there was an 83% gap between need and service delivery in the urban area and a 98% gap in the rural area. Thirty-two percent of the sample required either partial or full dentures (24% in urban and 49% in rural areas). Missing teeth is an important item not only because of social or functional aspects of daily living, but also as a barometer of quality of dental care. Generally, people who receive good and regular dental care will keep their teeth longer. Thirty-one percent of the total sample visited a dentist less than once every three years, which may well reflect the large number of missing teeth in these young developmentally disabled adults (26% of the urban sample had lost five or more teeth, while 12% had lost more than 10). These statistics, as well as many others obtained during the analysis of the dental examination findings, clearly indicate inadequate dental health care for these disabled persons and represent ineffective service delivery. To be sure, lowered intelligence (97% need dental health instruction), motor control and coordination problems in some (32% need help in performing oral hygiene), negative side effects of chemotherapy for seizure control (61% were taking anticonvulsant medication and had gingivitis), requirement of special dental management procedures (59%), etc., complicated the provision of regular dental services of high quality. However, the incidence and breadth of the dental problems observed in this sample support the specialized need this population has for such service, and the social and health effect that is created when the services are not provided.

Another example of premature "physiological aging" of the developmentally disabled person is the decrease in sensory functioning. Slightly more than one-quarter (28%) of the Philadelphia sample (36% of Chicago's sample) was found to have a hearing loss. Also abnormal eye findings were quite prevalent, with visual acuity defects in 31% of the total Philadelphia sample who could be tested.

Along with physiological changes that occur with the normal aging process, there occurs within our society increased social and economic dependency. As we indicated earlier in the summary of Chicago's findings, 42% of the existing problems in the adult population could have been prevented or improved to the point where current services would not have been necessary. Eighty-seven percent could have been treated in childhood so that their current problems would have been at least improved. Correctable problems, such as visual acuity, obviously should be sought. Similarly, decreased vision will inhibit the training of developmentally disabled persons. As the Chicago study indicated, "Many of the preventable problems (most of which were social and environmental rather than medical) converge to result in inability to work, earn an income and be independent. Upon examining this population of developmentally disabled adults it becomes rather clear how the many inadequately solved past problems have resulted in the extreme disability and handicap the group exhibits" (p. 45).

3. The needs of older DD adults cannot be met adequately by the generic service delivery system offered to the elderly. First of all, generic services and the coordination of services are not adequately available for the non-developmentally disabled aged, much less for the aged developmentally disabled who has been documented by

both the Philadelphia and Chicago studies to possess a large number of service needs which are currently unmet. Secondly, most service providers and planners consider the aging developmentally disabled population's service needs to be no different from the non-developmentally disabled aged population (Dickerson et al., 1974). Yet both studies indicate that the health and social status of the developmentally disabled adult directly relates to the previous extent and quality of service. The developmentally disabled adult represents an accumulation of unresolved medical, allied health, and socio-environmental problems which, while possibly making them older at younger ages, still represent additional service need areas beyond their "developmentally disabled" condition and their normal aging problems. For example, many of the subjects were observed to have problems in fine and gross motor control, communication difficulties, primary sensory deficiencies, and a host of other problems, both related and unrelated to their developmental disability. Since most of these problems originated in childhood and continue to compound each other as they are left unresolved, the resulting problems in adulthood comprise an array and severity of service needs quite different, qualitatively, from those typically associated with specific health disorders of elderly persons (cardiovascular problems, stroke and other cerebrovascular disorders, pulmonary diseases, senility, etc.) who have received adequate lifelong care. Thus, not only do aging developmentally disabled adults need more extensive services than normally aging persons, they also need specialized coordinated approaches and personnel to adequately evaluate and treat their problems.

4. *The health and social service needs of older developmentally disabled adults may relate to their geographic locale, the number and type of disabilities, socio-economic status, and residential setting*. The Philadelphia study was designed to compare specific groups of developmentally disabled adults according to certain factors considered to effect service need and availability. In view of the comparable methodologies and consistency of results, the broader based Chicago study permitted "cross-validation" of the findings of the Philadelphia study in several areas. It was found that the extent of service delivery needed by the adult consumer, on the average, was enhanced significantly by the following: (1) location in the urban delivery system; (2) possession of fewer developmental disabilities; (3) having epilepsy and mental retardation rather than cerebral palsy and mental retardation; and (4) middle or high socio-economic status. In contrast, (1) location in the rural delivery system; (2) having multiple handicaps, particularly mental retardation concomitant with cerebral palsy; and (3) low socio-economic status served, on the average, to decrease service delivery. Also found was that the urban delivery system had a greater need for coordination of services than for an absolute increase in money available for service delivery. The rural service delivery system needs included increased financial support, professionals, services (including transportation), and service availability close to the communities where the disabled live. Both systems needed upgrading of professional training programs to produce an increased number of providers trained not just within specialty disciplines, but in coordinated, interdisciplinary aspects of develop-

mental disabilities.

It was also found that, in general, a greater number of needed services were provided to those subjects residing in institutions than in the community. However, this greater number of met service needs was not necessarily equated with quality or effectiveness of service delivery, as will be discussed shortly.

Finally, it is interesting to note that neither age category (16-25 and 26-46) nor severity or mental retardation or cerebral palsy significantly affected service delivery. It is possible that the multiplicity of problems identified in the substantially handicapped samples studied was so great generally, that the potential importance of these factors (as measured) were undetected.

Given the nature of the studies' other findings, the above variables which did affect service delivery to relatively young developmentally disabled adults will most likely continue to exert significant influence on their service needs as they age.

5. The effect of deinstitutionalization can be expected to have minimal impact on the existing community service delivery system to developmentally disabled adults. This last implication, derived from the Philadelphia and Chicago studies, has less to the with the aging process, but nevertheless is critical for the planning and implementation of a service delivery system for developmentally disabled persons. The current trend towards deinstitutionalization based on the principle of normalization has raised a number of issues regarding the poor quality of institutional care and the inability of community delivery systems to manage the additional service demands which would be created by the influx of new consumers.

Approximately one-third of the subjects evaluated in the Philadelphia study were currently residing in an institutional facility. Comparing the service needs of institutionalized and noninstitutionalized subjects as identified by the interdisciplinary clinical team, it was determined that significantly ($p = .003$) more service needs were being met for those subjects residing in institutions than in the community. It would appear that one of the advantages of residential services as seen from our data is that a greater range of services were available to meet the needs of the clients in our sample than are typically found in community facilities. However, the sampling biases inherent in the institution's selecting which of their clients were to be included in our sample, the lack of data obtained regarding the frequency and effectiveness of the services delivered, as well as the global nature of the concept of "met service needs" mitigate against the validity of making an inference about the quality of institutional services based on these data.

What is perhaps more important are the conclusions from both the Philadelphia and Chicago studies regarding the huge gaps in service delivery to developmentally disabled adults living in the community. Again, comparing the service needs of the adults in the Philadelphia study who reside in the community and residential facilities, the community subjects require slightly more "new" services than residential subjects (an average of 15 per person vs. 13), have a continuing need of currently delivered services similar to their institutionalized peers (4 and 3, respectively), and have an equal number of anticipated new service needs in the future (4 each). To be sure, all subjects in the Philadelphia study were multiply handicapped and, therefore, required more services than those with single handicaps (as indicated from the Chicago study). However, the data indicate similar service needs regardless of residence, and maybe slightly higher needs if currently living in the community. Thus, the argument that deinstitutionalization is not particularly feasible due to extra service demands placed on the community is not supported with the current data.

According to Baumeister and Butterfield (1970) and Butterfield (1969), only about 5% of the mentally retarded in the United States then resided in institutions, about half of which were children. (And, incidentally, more money is spent to maintain them than is spent for any of the public programs which serve the remaining 95%.) While residential services do comprise an important part of the service continuum (Tizard, 1969), even if all the developmentally disabled persons residing in institutional facilities were transferred to the community, the total impact on the service delivery system would be minimal (perhaps 5% to 10% increased service need) in comparison to the unmet needs of those developmentally disabled adults who already live in the community.

The inadequacy of services for the aging developmentally disabled adult results from, at least in part, their increased health and social needs, from inadequately and/or ineffectively delivered services in the past, and from the limitations of the current system. The development of comprehensive and coordinated service delivery systems which provide adequate, appropriate, and timely services to the DD population is the primary need identified and recommended by both the Philadelphia and Chicago studies.

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## TABLE 1

## Descriptive Characteristics of the Study Sample

| Disability & Location | Number | (%) | Age | | Sex | | Race | | SES[7] | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | 1<br>Y | 2<br>O | 3<br>M | 4<br>F | 5<br>C | 6<br>B | Low | Mid-High |
| CP-MR[8] TOTAL | 63 | (53) | 39 | 24 | 40 | 23 | 56 | 7 | 47 | 12 |
| Urban | 40 | (34) | 26 | 14 | 25 | 15 | 33 | 7 | 27 | 10 |
| Rural | 23 | (19) | 13 | 10 | 15 | 8 | 23 | 0 | 20 | 2 |
| EP-MR[9] TOTAL | 56 | (47) | 34 | 22 | 29 | 27 | 46 | 10 | 46 | 6 |
| Urban | 40 | (34) | 25 | 15 | 18 | 22 | 30 | 10 | 33 | 4 |
| Rural | 16 | (13) | 9 | 7 | 11 | 5 | 16 | 0 | 13 | 2 |
| TOTAL DISABILITY GROUP | 119 | (100) | 73 | 46 | 93 | 18 | 102 | 17 | 93 | 18 |
| Urban | 80 | (67) | 51 | 29 | 60 | 14 | 63 | 17 | 60 | 14 |
| Rural | 39 | (33) | 22 | 17 | 33 | 4 | 39 | 0 | 33 | 4 |

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1. Y = Young adults defined as 16 to 25 years of age
2. O = Old adults defined as 26 years of age and older
3. M = Male
4. F = Female
5. C = Caucasian
6. B = Black
7. SES = Socioeconomic Status as defined by Hollingshead and Redlick's Two Factor Index of Social Position. The required information was not available for 6.7% of the sample (8 subjects).
8. CP-MR = Cerebral palsied mentally retarded subjects
9. EP-MR = Epileptic mentally retarded subjects

WORKSHOPS I & II
Workgroup 1
Group Leader: Paul Boodoian
Group Reporter: John Keiter, Ph.D.

The discussion on the definitions of aging, aged, developmental disabilities, mental retardation, cerebral palsy, epilepsy and autism showed a wide variety of thought. The majority of the time was spent in discussion of the terms "aging" and "aged." Questions were raised as to what each of these terms means. "Is aging a process that is the later half of life?" "Is aging the loss of skills and the point where services or aides are needed?" "Does one define age on a chronological, psychological, sociological, or biological basis?" Since self-image is important to everyone, it was concluded that age should not be stated in terms that have or could have negative impact. Since it is politically necessary to define these terms, the following definitions were the conclusions of this group, many being adopted from agency definitions:

## Definitions

AGING is a total life process that begins with birth and continues to death that includes bio--socio--psychological aspects.

AGED is the continuing unfolding of life process after reaching maximum maturity which may or may not have an impact of change upon the lifestyle of an individual; which is dependent upon inherent factors of the individual.

DEVELOPMENTAL DISABILITY is a disability which originates before an individual attains age 18, continues, or can be expected to continue indefinitely and constitutes a substantial handicap. It describes the handicap of an individual whose needs cannot be met adequately and may not be benefitting from those social, educational, vocational, recreational, medical or other resources which generally are expected to be available to other non-handicapped individuals in the community.

AUTISM is a syndrome first appearing in very early years of life, which may be characterized by extreme withdrawal, language disturbance, inability to form affective ties, frequent lack of responsiveness to other people, monotonously repetitive motor behaviors, inappropriate response to external stimuli, and obsessive urge for the maintenance of sameness.

EPILEPSY is a symptom of an underlying neurological disorder characterized by brief episodic attacks called seizures or convulsions.

CEREBRAL PALSY is a non-progressive pathologic lesion in the developing infant or child's brain causing permanent motor impairment.

MENTAL RETARDATION is an intellectual and adaptive behavior deprivation characterized by an IQ score of two standard deviations below the mean.

In light of the Oregon presentation that priorities are dependent upon many variables (which may include local resources, services available, perspective of council members and others), it was concluded that to prioritize needs on a national level is ridiculous. Each state, county, city or care provider will face needs for services that could help to provide a better life for the aged developmentally disabled person.

These needs were discussed on many levels. They were divided into two categories: the needs of the aged developmentally disabled individual, and the needs of the professionals who deal with the aged developmentally disabled individual.

(1) AGED DEVELOPMENTALLY DISABLED NEEDS

Adult Education
  a) death
  b) sexual
  c) social
Counselling
Health & dental care
Housing
Income maintainance
Integration into society
Protection & advocacy system,
Respect of individual rights
Transportation
Vocational training

(2) PROFESSIONAL NEEDS

Incentive program to stay in field
Information referral system (intragency communication)
Ombudsman
Professional training

These needs are not prioritized, just alphabetically listed. In discussing these needs, we felt the one thing that was lacking was client input.

## WORKSHOPS I & II

Workgroup 2
Group Leader: Julie Meyerson
Group Reporter: Ann Carswell

Work Group 2 was composed of twelve persons representing diverse geographic areas and orientations from a variety of disciplines concerned with aging and aged developmentally disabled persons. Group leader Julie Meyerson proved to be an excellent moderator as she successfully coped with the tasks of keeping the group focused on workshop goals and promoting participation by each group member. After a brief period of introduction and orientation to each participant's frame of reference or major interest, the group moved into discussion of definitions.

Workshop I focused on the task of defining terms. The first two terms, aging and aged, were the most difficult to define. It was felt that these terms carried negative connotations of debility and dependency and the group wanted to foster a more positive attitude. Each definition was the result of group effort with much discussion and amending until a consensus was reached. The following are Work Group 2's definitions of the designated terms:

AGING describes a developmental process affected by physical, mental and environmental changes starting at conception and ending at death.

AGED describes the attainment of a maturity of years characterized by the changing of developmental and vocational activities and by increasing needs for physical care and leisure time activities.

DEVELOPMENTAL DISABILITY is a condition (mental retardation, autism, cerebral palsy, epilepsy, and other neurological conditions) occurring before the age 18 and continuing for life, that constitutes a limitation in some functioning in the mainstream of life.

Two individuals recommended a change in the definition of developmental disability in which the definition would be expanded to delete age limits and to include conditions affected by mental and environmental changes brought about by physiological changes.

AUTISM is a childhood condition characterized by extreme withdrawal, communication problems and sometimes mental retardation.

EPILEPSY describes symptoms of some disorder of the brain characterized by seizures or convulsions.

CEREBRAL PALSY is an organic disorder of the brain characterized by paralysis, weakness and poor coordination and sometimes mental retardation.

MENTAL RETARDATION is a condition occurring before age 18 and continuing for life, resulting in a person's being slower to learn and slower to apply what has been learned to daily life.

The goal of Workshop II was to identify and prioritize service needs of the aging and aged developmentally disabled population. Group 2 went a step further in identifying the impediments and obstacles in meeting these needs. Due to the lack of time and lack of homogenity within the developmentally disabled population, those service needs were not prioritized but are listed in order of discussion. The listing of needs and obstacles is a compilation of input from all group members.

| Service Needs | Obstacles |
|---|---|
| 1. Improved inter- and intra-agency planning and coordination. | -- concern with turfdom;<br>-- competition for funding;<br>-- legislative restraints & political barriers;<br>-- conflicting standards especially in eligibility; |
| 2. Case management. | -- lack of training for counselors;<br>-- society's non-acceptance;<br>-- efforts not coordinated;<br>-- parental fears and attitudes; |
| 3. The training of staff, parents, clients and the public. | -- lack of commitment;<br>-- low priority;<br>-- lack of funds;<br>-- lack of trained staff; |
| 4. More positive development of broad and specific programs of public education, including professionals, to promote acceptance and understanding of older developmentally disabled persons. | -- low funding priority;<br>-- negative stereotypes of elderly and developmentally disabled;<br>-- fear of developmentally disabled as dangerous, a menace, etc.;<br>-- low societal expectations;<br>-- lack of valid information concerning behavior;<br>-- lack of public exposure to developmentally disabled;<br>-- institutionally-oriented society;<br>-- low self-concept of developmentally disabled; |
| 5. Advocacy. | -- lack of lobby/constituency;<br>-- children's services get higher priority;<br>-- lack of professional knowledge of rights and services;<br>-- fear of bucking the system;<br>-- lack of citizen commitment;<br>-- unrealistic outcome expectation by society; |
| 6. Adult protective services. | -- lack of development and implementation of service on the state level;<br>-- conflict between regulations and human needs;<br>-- lack of regulatory enforcement procedures for institutions;<br>-- lack of administrative review process; |

| Service Needs | Obstacles |
|---|---|
| 6. Adult protective services (con't.) | -- lack of awareness of abuse and channels to correct such abuse;<br>-- conflict of interest in regulations and enforcement thereof; |
| 7. Preventive and support services (including homemaker and health sevices, day care and respite care). | -- lack of respite care;<br>-- inadequate cost effectiveness data;<br>-- no documentation to support needs<br>-- lack of public awareness;<br>-- lack of funding resources;<br>-- refusal to rearrange program priorities;<br>-- lack of professional interest and expertise;<br>-- lack of knowledge of referral resources;<br>-- inaccessible leisure time activities; |
| 8. Alternative living arrangements. | -- options not developed;<br>-- local zoning restriction;<br>-- inappropriate regulations;<br>-- institutional attitudes;<br>-- lack of commitment;<br>-- developmental objectives not implemented;<br>-- lack of continuing assessment for appropriate placement;<br>-- architectural barriers; |
| 9. Transportation. | -- geographic limitations;<br>-- lack of mechanics to implement system;<br>-- lack of accessibility;<br>-- lack of funding;<br>-- lack of utilization of existing vehicles;<br>-- regulation problems such as insurance costs; |
| 10. Social and recreational services. | -- lack of church involvement;<br>-- lack of availability of services;<br>-- lack of trained staff;<br>-- no developmental objectives;<br>-- public stereotyping and labeling. |

Additional service needs identified by the group included opportunity for employment, modifications in financial assistance programs, counseling and referral services, and research and evaluation.

WORKSHOPS I & II
Workgroup 3
Group Leader: Edwin Butler
Group Reporter: Shirley Bengtson

A workshop participant reported how she became involved with aging and aged developmentally disabled persons. She was checking out two state nursing homes which housed more than 200 older or disabled mentally retarded persons. She used a simple profile to determine if there were persons there who should be in mental retardation developmental programs. Red signified "can do." Blue meant "could do with training." Green meant "forget it." A resident approached her and stated, "I go back to state hospital." She asked why. The resident replied, "I came out all blue." "What would you do at the state hospital if you went back there?" "I go to workshop and learn. Then I go to work." "What are we going to do this afternoon?" "Birthday party!" "Whose birthday is it?" "Mine." "How old are you?" "88!" "Why should you go back to the state hospital? Why don't you retire?" "I retire!"

Workshop I was assigned formulation of definitions of developmentally disabled, aging, aged, autism, cerebral palsy, epilepsy, and mental retardation. After much discussion, the following definitions were adopted:

AGING is a birth to death process, but the definition from this group should exclude the younger population. "The developmental process characterized by a need to adapt to biological, psychological, and social change, with recognition of possible increased vulnerability invoking new coping methods."

AGED describes the older segment of the population characterized by: (1) significant losses related to physiological, psychological, and social personal changes; and (2) chronological age eligibility for certain public services, rights, and restrictions.

The Workshop group accepted the definitions for all the disabilities as proposed by the National Advisory Council for Developmental Disabilities.

Workshop II followed the assignment of identifying and prioritizing service needs of the aging and aged developmentally disabled population. As the participants came from such diverse backgrounds and interests, this assignment allowed for many participants to tell of their problems and their achievements in meeting the needs of this population, each with emphasis on the particular disability group with which the participant worked. Finally, 14 service areas were identified. These are listed by priority. However, after number 6, there was lack of concurrence on which needs took precedence over others. Needs 7 through 14 have nearly equal priority:

1) Coordinated professional and public education and reorientation. This includes public awareness. It also includes changing the older public's thinking that the developmentally disabled population should be segregated.
2) Acceptance and inclusion into recognized funded programs to achieve socialization. This would be a mandated inclusion. This should include membership in the program, or at least special inclusion in senior citizen groups that use funds allocated for senior citizens. If the developmentally disabled population should have senior citizen membership in groups but maintain their own separate chapters,

this would go against "normalization."

3) Advocacy is needed in all areas.

4) The developmentally disabled population should have the same criteria for use of residential facilities, nursing homes, and intermediate care facilities as the general population. There should be sufficient alternatives in housing to meet the needs of developmentally disabled persons.

5) There should be funded productive work activity designed individually for personal reward, for development, and for maintenance of functioning level. There should be special emphasis on the severely impaired person.

6) Health care should be upgraded and should cover all needs. There should be financial assistance as needed and there should be equal availability of services.

7) Specialized transportation should be provided to both rural and urban populations.

8) Expanded in-home care services are needed.

9) Physical fitness programs should be developed.

10) Respite programs for both caretakers and developmentally disabled persons are required.

11) Crisis communication, consultation, and information and referral should be easily available.

12) Flexible vocational training and developmental programs need to be implemented.

13) Day care service should be established.

14) Recreation programs should be provided.

There was insufficient time for the Workshop group to go into such matters as human sexuality and religious needs, but the group did not want to exclude these.

## WORKSHOPS I & II

### Workgroup 4

Group Leader: Ronald Stevens
Group Reporter: Robert Ford

The goals of this workshop were (1) to determine each participant's frame of reference or major interest with regard to the conference; and (2) to achieve a working consensus around primary definitions.

Ronald Stevens began the session by having each member introduce him/herself by name, nickname, and field of expertise. It immediately became apparent that the fields of expertise covered most of the disciplines that deal with developmental disabilities.

Arlene Judy, a parent of an autistic son and representative of the National Society for Autistic Children, gave important input as a consumer and parent as did Carol McKy, a consumer and advocate for Nursing Home Affairs. Manuel Bustamante or "Manny," also an advocate and Consumer Agency Representative, served with the two ladies to give the consumer-advocate point of view.

Doris Haar represented the federal agency with Dr. Raymond Holmes and Robert Ford represented state agencies. Institutions and the medical community were represented by Dr. Miguel Cruz. Representing providers was Ronald Stevens supported by the experts from several University Affiliated Facilities, Nola Thomas, Mike Gallery and Stanley Rest.

It was apparent from the beginning that the members of the workshops were a rebellious group of individuals who would not be overwhelmed by one idea. This factor made it apparent that a consensus would be difficult to arrive at but once one was reached, all aspects of the goal or in this case, the definition, would have been explored. The time factor involved in this type of exploration, however, dictated that all definitions could not be handled in the session. After defining aging and aged, the group agreed to accept the Federal legislative definitions of autism, epilepsy, cerebral palsy, and mental retardation.

To arrive at the goal of a definition for aging from a group so varied in frame of reference proved exciting and at times humorous. Such a word as "aging" has many considerations to be contended with. Considerations such as funding sources can have considerable impact on how a definition is handled. The group agreed that presently many professionals and agencies assume that aging only takes place during a certain age point, (i.e. after age 55). This assumption was offered in the discussion, but an overwhelming number of participants would not agree that this should be included in the definition.

The group also rejected the suggestion that aging had an aspect of dependency and felt it should not be included in the definition. After a great deal of discussion the group concluded that aging could be defined within functional terms. The groups agreed that the biological definition of from "birth to death" was most appropriate. Since this type of statement did not describe the process of aging, but only suggested the presence of same, Dr. Miguel Cruz offered the refined wording which was accepted by the group. The accepted definition submitted by Group Four is as follows: "Aging is a process of development that continues throughout life."

"Manny" felt that more needed to be said about aging and its relationship to funding. To assure that funding would be available, he suggested "Aging is a process that needs to be funded."

Having completed the definition of aging, Group Four proceeded to the task of defining "aged." It was suggested that "aged" could be categorized in terms of chronological age. When the age of 50 was suggested, one member immediately felt this was "labeling" and the discussion that followed made it evident that the word "aged" was disliked and had negative connotations such as "preparation for death." Since the negative feelings about the word could not be overcome, the group felt the definition of aging included aged. However, if it had to be defined, one could call it "the later part of the aging process."

It was felt by the group that the goals for Workshop I were achieved.

The goal of Workshop II was to identify and prioritize service needs for the aging and aged developmentally disabled population.

The group began the discussion in a subdued fashion in the beginning, probably due to a full, secure feeling experienced following lunch. However, this atmosphere did not last long and the discussion returned to the lively style of the earlier workshop. Many needs were identified such as those mentioned by other groups, i.e. transportation, health services, financial assistance etc.

Doris Haar of the Federal agency pointed out that the needs mentioned were not different from all aged or actually all people. What was really needed was to separate those needs that might be unique.

One glaring problem pointed out was the lack of knowledge as to how many aged developmentally disabled persons there are and where this population has been in the past. Thus, one need was a system to identify and locate the aged person who happens to be developmentally disabled.

The group felt that probably most of the basic needs such as domiciliary care and health care were being met, but the concern was how adequately. Carol McKy indicated that a study indicated that 50% of the nursing homes are below minimum standards of care.

Other needs discussed included alternative living, respite care and mental health, but the group considered the freedoms guaranteed under the Bill of Rights of the Constitution, (i.e. freedom of choice and freedom of sexual expression) as the most pertinent needs. These needs indicated that strong advocate and self-advocate programs should be developed.

A dilemma developed when the group tried to prioritize the above mentioned needs. The group could not agree as to which came first, "the chicken or the egg." It became apparent that depending on circumstances, all the needs were interdependent. Each need was dependent on the other needs being met, in other words to quote an old proverb, "no need is an island unto itself." The workshop drew to a close with the recommendation that the needs not be prioritized.

WORKSHOPS I & II
Workgroup 5
Group Leader: John Humphrey
Group Reporter: Jo Hildebrand

## Definitions

This group struggled with the assignment of defining terms and categorizing people according to age so services could be provided. It was difficult to concentrate on the aged developmental disabled when there was consensus that all developmental disabled persons are in need of service delivery from cradle to grave. There was a realization that we cannot meet everyone's needs and still give full attention to the aged developmental disabled. If no one concentrates on this specific aged group, they will have a tendency to get lost in the crowd and never receive adequate service delivery.

Defining an AGED DEVELOPMENTAL DISABLED individual focused dicussion on the difference of aging versus aged. Aging was viewed as being a developmental process that begins at conception and continues throughout a lifetime. The term AGED was referred to as a chronological number that is attributed to an individual over a certain age--that specific age varied among participants of this group anywhere from ages 25 to 45 to 65. For purposes of providing services and pursuing funding sources, the arbitrary age of 60 was chosen.

Focus of the group narrowed into discussion in the following areas: (1) Are the life processes different for the aged developmental disabled individual in the areas of physical, psychological, social or emotional functioning? A participant of the group said that an aging developmental disabled person at 45 has a very difficult time because of the lack of social, educational, and vocational services, no place to live and lack of recreational and rehabilitative services. Does this lack of services become even more insurmountable as one grows older? 2) Need to research funding sources as it relates to this specific age group. Sixty years of age was chosen arbitarily to meet Administration on Aging guidelines.

The aged mentally retarded, refers to a mentally retarded individual, who through the normal aging process at certain chronological age, develops difficulties in functional levels.

Impediments to the development of this service would be: society's lack of acceptance, inaccessability to services, and difficulties in funding.

## Development of Programmatic Services

There is a need for the mobilization of coordinated service delivery to those in need of the services. This effort has the potential to create an ongoing service delivery system, with the need to continuously develop new services to meet future needs.

Impediments to the development of services are: lack of funding, fragmentation of services, lack of trained professionals, mobility problems of those who need the services, absence of documentation systems, and lack of public knowledge and empathy for service development.

Under this category, adequate health maintenance would include access to appropriate medical, nutritional, social, recreational, and spiritual services. Recommended under this context is dental care. Dental care for the older adult is a specialty, and dental care for the aged developmental disabled is even more specialized.

There was also discussion on relocation trauma planning. The movement of an individual from one location to another can cause physical and/or psychological problems without adequate planning.

## Development of Transportation Services

There is a tremendous need to have an effective transportation system that can either provide direct services to individuals or get the individuals to the service. All the services in the world can be available, but if there is no feasible way to get to the service, then many individuals still will not be served. Everyone has the right to mobility to meet their needs.

# WORKSHOP I & II

## Workgroup 6

Group Leader: Rebecca Kutz
Group Reporter: Mary Frost

The dozen of us participating in Group 6 of Workshops I and II came from varied geographical locations ranging from the eastern seaboard to the far western area of the Rockies with varied backgrounds including music therapy, program development both within and outside of the institutions, nursing, social work and academia. As varied as were our frames of reference and our vision as to how we personally related to defining aging and aged--definitions with which we struggled mightily for three quarters of the time allowed--there was no conflict as to our individual and collective concern for the welfare of those people identified as developmentally disabled during their various stages of growing. Our attempts to define aging and aged ranged from the philosophic to the pragmatic. Even those who elected to relate to a specific chronological stage could not come to consensus as to what that age should be.

Some suggested the age of 21, a critical age, because that is when there is a break in service delivery and when access to the public school system ends. There is often no structured service available to take up the slack. Some suggested that perhaps a person should be considered to be aging at 30 or 35, the stage where the physical peak is attained, or maybe it is more logical to settle for the age of 65 when the average working person is eligible for retirement. After much soul searching there was most concurrence with the definition of aging as "as a process that begins with the first breath of life and continues through varying stages until the last, with a tendency to coincide with the chronological age but recognizing the process as highly individualistic."

However, with guidelines too broad, abuse is more apt to be perpetrated. Inasmuch as the purpose of this conference is to initiate help and funding, the group accepted the responsibility for setting priorities. One rather innovative proposition was that in considering aging, not only the process that goes on within the developmentally disabled individual, but also that which goes on within the spectrum of the family unit should be taken into account. One example given was the person with Down's Syndrome, frequently born to parents of more advanced age than the average. By the time that person reaches 20, the parents are often in their sixties and their ability to continue care becomes increasingly limited. Though the majority agreed with this concept, two of the group preferred to define aging in terms of a programmatic approach rather than as a process.

In attempting to come to terms with a definition for "aged" our internal conflicts continued to some degree, although it was generally accepted that chronological age is only part of the picture. One's state of health has a large bearing, but state of mind (attitude) has an even larger bearing in that someone who manages to remain physically and/or mentally active appears less aged. To determine whether developmentally disabled persons do indeed age more rapidly than the general population, it is necessary to have hard data which is currently unavailable.

Two of our group noted that people with developmental disabilities between the ages of 21 and 65 are among the population most apt to be neglected. One of the problems appears to lie in the public school system where those in the "trainable" classes often are not trained in viable vocational or even basic survival (residential) skills. "What are you training them for?" is the question thrown back to haunt the school officials who consider their duty completed once a person has attained majority. Even though schools have a broad mandate to educate handicapped children, this is often grossly overlooked.

Three basic components of being aged are the result of the interaction of psychological, social and biological changes. Does the developmentally disabled person age faster? That is debatable from our perspective. However that is something that needs to be clarified so that if it is indeed a factor the National Council on Aging needs to be challenged. They have defined the age of sixty-five as a cut off point. Perhaps our developmentally disabled people should request exceptions to using chronological ages as criteria for acceptance to services with chronological age being used only as a guideline. Often people who have lived most of their lives in the sterile atmosphere of an institution become retarded (slower) due to environmental deprivation and lack of any meaningful stimulation. On the other hand, if chronological age is deleted as a criterion, it will be necessary to be very precise about the establishment of priorities and services to be delivered.

Habilitation and rehabilitation services in rural areas are usually fragmented with no programs to pick up those age 21 and above who are no longer eligible for public school services. Often in urban areas there are existing programs for the general aged population to which the developmentally disabled person might be referred. However, because of the use of the National Council on Aging's definition as criteria for acceptance, they are rejected.

Most participants in Workshop I were uncomfortable with the concept of age 21 being considered aged even though it was for programmatic purposes and felt the need for improved research and data collection in this area.

The remaining quarter of our time which was used to define the next five categories was less complicated because the group basically used the already established definitions.

The group defined the following terms.

DEVELOPMENTAL DISABILITIES is a disability attributable to mental retardation, cerebral palsy, epilepsy or autism or other condition related to mental retardation with similar impairment of mental functioning, adaptive behavior requiring similar treatment or services (including dyslexia when secondary to any of the above) originating before the age of 18, expected to continue indefinitely and constituting a substantial handicap to one's ability to function normally in society.

Further discussion centered around the thrust to change the definition to include dyslexia even without the current linkages, as well as broaden the service categories and increase the age to 22. One of the present group to benefit would be the person who develops a seizure disorder after the age of 18. A valid argument against broadening the service categories is that it may result in diluting the ability to serve those most in need. With an enlarged base, the problem of funding and serving is apt to increase correspondingly.

It was felt that there should be a de-emphasis on using etiology just for purposes of classification unless directly related to service needs and the most critical concern being the adaptive behavior deficit, while emphasizing service needs as the bottom line.

AUTISM is a severe disorder of communication and behavior beginning in very early childhood (most like childhood schizophrenia); monotonously repetitive behavior, with stipulation behaviors which may continue into adulthood.

EPILEPSY is a recurrent seizure disorder secondary to recurrent abnormal electrical discharges within the brain which would affect one's ability to function normally in society. It can present a temporary or intermittent handicap depending upon the type. In 80% of the people in the United States the seizure activity can be controlled.

CEREBRAL PALSY is a group of dysfunctions with a variety of symptoms; all brain centered and affecting muscular control and sensory functions. Types are: spastic (stiff), athetoid (involuntary uncontrolled movements), and ataxic (disturbed sense of balance and depth perception).

MENTAL RETARDATION is the slower learning ability, or appearance of slower learning ability of one lacking in either intellectual skills, ability to reason logically, adapt in socially acceptable way to one's surroundings. The condition is manifested during the developmental period.

Our group had little difficulty in identifying service needs of the aging and aged developmentally disabled population. One after another area of acute need which were seen as being insufficiently addressed tumbled from our lips and it was obvious we all felt deeply frustrated by the "lacks."

The attempts to prioritize these perceived needs resulted in provoking much heated discussion and created a much greater struggle. Within the broad spectrum there was concern expressed that the needs were all so important it was impossible to designate any one higher than the other. Then reality dictated the necessity and after all the soul searching it was most interesting to note that in the final analysis we prioritized the needs in exactly the same order that they were originally discussed.

Thus health care and all the associated services was established as being the most pressing in the demand for attention.

## Health Care

Some of the services required to provide adequate health care are:

1) Home Health Care/Homemaker Service;
2) Home nutrition counseling -- realistically geared to the appropriate level of competence to make it meaningful;
3) Nutrition services -- Congregate meals, Meals on Wheels;
4) Dental Care -- emphasized because it is an area significantly less popular for funding, therefore it is given less attention. (Or is the funding lacking because it is given less attention?) Regardless, poor teeth, poor dentures, or total lack of dentures all contribute to inadequate nutrition with a resultant decrease in health and general well-being. The money that is saved by neglecting dental needs, frequently must be spent less advantageously

for remediation in a sort of "nobody wins, everybody loses" sense; and

5) Clinical facilities.

## Residential Alternatives

Some of the residential services needed are:

1) Provision of quality continuum of service from a relatively restrictive to a highly independent environment;

2) Transition programs -- whereby institutions provide outreach and assistance in integrating people gradually into community programs, while helping them to achieve daily living skills;

3) Family homes -- using a natural or surrogate family. In considering placement of a developmentally disabled person, it is often taken for granted that the place of choice is the individual's natural family home. It was pointed out that this possibility should most certainly not be overlooked if it is the family's sincere desire to maintain their aging relative. However, the normal expectation is that a child tends to leave home by the age of twenty, and it may be more fair and realistic to allow a similar independence to the greatest extent possible for the developmentally disabled person by providing a surrogate family;

4) Respite care situations should be made available regardless of whether placement is with the natural or surrogate family. Respite care should not be strictly for crisis situations, but should be for the purpose of preventing

burn-out, and to allow for more space in the togetherness. Respite care and appropriate "sitter services" is another community maintenance program that is most apt to be neglected in the planning; and

5) Day Programs - training for care providers to enable them to teach independent living skills to the developmentally disabled person on an ongoing basis as opposed to simply functioning in a caretaker status.

Advocacy, Public Relations and Lobbying

Lack of adequate preparation of the community for the deinstitutionalization of developmentally disabled adults has hindered their acceptance into the community. The necessity for adequate preparation of the community is equally as important as the preparation of the individual. In most instances this has been woefully absent, and has been a deterrent to acceptance.

Additional needs in this area are:

1) Education of service providers and employees;

2) Education of personnel involved in the criminal justice system.

Most frequently without that education, naive offenders are treated in the same manner as the average citizen. They are provided wit little understanding or compassion. While the offender's disability should be no excuse for improper behavior, the methods of dealing with these problems should include increased sensitivity. Punishment should be appropriate to the offense and the offender;

3) Access to legal services;

4) Information and referral services;

Churches should be persuaded to include the developmentally disabled person in its congregational activities which would encourage integration. It was felt that churches were in a unique position to provide leadership in this area, achieving maximum benefits at minimal cost.

## WORKSHOPS III & IV
Workgroup 1
Group Leader: Michael Gallery
Group Reporter: Diane Delmas

Our group was assigned the task of reviewing health care and recreation needs for the developmentally disabled population and identifying the impediments that could possibly prevent implementation of programs geared toward meeting those needs.

Health care was seen as a very important need for this special population and prior to discussing the specific services and impediments, the group determined that more specific data is needed with regard to standards and human and legal rights for the developmentally disabled aged persons. It was also determined that more research is needed regarding aging in the community versus aging in the institution.

Medical services for health maintenance, dental care, and nutrition were the three outstanding services discussed. The group then identified the impediments to implementing needed services as follows:

1) Medical staff unwilling to work with developmentally disabled aged persons;
2) Services not personalized or supportive;
3) Medical and nursing staff not trained to work with this population;
4) Lack of public transportation especially in rural/deprived areas;
5) Distances to services from deprived areas;
6) Physicians prefer not to treat Medicaid patients;

7) Dental fees too expensive;

8) Lack of resources;

9) Lack of nutrition programs to teach developmentally disabled aged persons about adequate diets;

10) Availability of manpower (physicians and medical-care staff);
    a) Distribution;
    b) Medical personnel prefer not to go to deprived areas;
    c) No outreach;

11) Coordination of services (e.g., casemanager/physician).

Suggested methods in resolving some of these impediments are outlined below:
    a) Creating incentives for medical professionals such as awarding stipends;
    2) Training local people in the deprived areas (paraprofessionals);
    3) Better and/or more effective case management.

To alleviate negative attitudes among the medical profession and other health care professionals toward developmentally disabled aged persons it was suggested that they receive more exposure, more in-depth training in medical schools and that in-service training be provided for those already in the field (i.e. medical doctors working in institutions).

In discussing the impediments in implementing recreational activities four areas of concern were discussed as follows:

1) Hesitancy of significant person in taking developmentally disabled persons out in the community;

2) Hesitancy of developmentally disabled person to go out;

3) Clients' lack of choice to participate in recreational programs;

4) Inappropriate adult activities disregarding age-appropriate recreation and developmental appropriateness.

Ways to alleviate these impediments were identified as follows:

1) Educate and involve significant persons in activities with developmentally disabled persons;

2) Expose the client to age-appropriate or developmental-appropriate recreational opportunities or options;

3) Give the client a choice to use generic agencies' recreational programs.

Measures to be considered in getting the community to accept developmentally disabled aged persons in recreation activities included upgrading the appearance of the clients and not calling attention to or asking for discounts or free hand-outs. It was also agreed upon that the public must be educated as to the rights of these individuals and that community facilities should have no architectural barriers.

The group decided that it was not important to discuss what forms of recreation are available but that the important thing to note is that those involved in recreation programming identify the options and then encourage clients to utilize those culturally normal options.

Provisions of age-appropriate activities:

1) Find out what other elderly people are doing and then make sure that the developmentally disabled aged are given the

same opportunity to be involved in similar activities.

2) Opportunities for space and privacy with the opposite sex should be provided so that the aged developmentally disabled person can develop interpersonal relationships.

In Workshop IV the task was to identify new designs and guidelines for service and to design models for the services. We felt that it was not possible to design an appropriate model due mainly to one limitation: there was no consumer participation. We elected to discuss further what was summarized in Workshop III.

WORKSHOPS III & IV
Workgroup 2
Group Leader: Robert Day
Group Reporter: Robert Holmes

## Obstacles to Service Delivery in the Area of Employment

Our committee identified several areas as obstacles to employment for the aged. They are as follows: (1) transportation shortages; (2) employer prejudice (i.e., fear of hiring the handicapped); (3) the appearance of the client; (4) attitude of employer and client; (5) lack of incentives; (6) lack of funding resources; (7) unrealistic societal goals for clients; (8) conflict between regulatory agencies (Federal, state & local); (9) cost effectiveness; (10) lack of public awareness; (11) refusal to rearrange program priorities (i.e., options are not developed); (12) lack of commitment by the employer; (13) political processes; (14) lack of advocacy; (15) lack of utilization of school buses when they are not in use; (16) state of the national and local economy (fixed income, for example); (17) lack of vocational training & counseling; (18) lack of precursory services such as occupational therapy, physical therapy and speech pathology, including loss of Medicaid, homemaker services, food stamp programs and sometimes even HUD rent subsidies.

## Recommendations to Remove Obstacles

Transportation. Federal, state and local funds should be used to support transportation for the aged. Also, foundation money should be sought to help this population. Regulation 504, which includes architectural barrier-free construction, can also be used with regard to transportation for this population. The Highway Act for the Elderly & Handicapped may be used, which requires bids for transportation vehicles. State Highway Departments often accept bids and applications under this particular Act. In New Jersey and Kentucky, transportation vans are used for the handicapped. School buses, when they are not in use for children, should be used for the aged as well as the utlization of car pools. Title XIX funds can also be used to supplement transportation assistance for the aged. Multi-dimensional approaches are required by Federal, state and local governments through their mandates.

Appearance. The aged can benefit from counseling and training resources to enhance their appearance.

Attitudes. Clients can be trained to have more appropriate attitudes, and the community can be exposed to advocacy which can help their attitudes.

Lack of Incentive. It is recommended that the service delivery system be revamped in order to use medical services, to provide counseling, particularly pre-vocational counseling, and to provide homemakers with training in activity of daily living skills.

Lack of Funding. CETA Programs can be used to remotivate individuals who have training needs.

Advocacy. The group determined that there were several obstacles to implementing advocacy programs for the aged. They include: (1) lack of lobbying power; (2) the prioritizing of children's services over services for the aged; (3) unrealistic outcome expectations by society; (4) the aged person's lack of professional knowledge of rights and services; (5) the aged persons fear of "bucking the system"; and (6) lack of citizen and community involvement.

Our committee recommended that, in terms of lobbying power, the aged should utilize the following groups: (1) local parent groups, specifically ARC's; (2) the Grey Panthers; (3) American Association of Retired Persons (AARP); and (4) advocacy groups representing various disabilities. These advocacy groups should meet and share ideas. They should educate the community and encourage agencies serving the elderly to plan an advocacy role.

To enhance professional knowledge of the rights and services that they are entitled to, the aged should be engaged in training programs, be exposed to informational referral systems, and participate in local advisory boards. They should inform large businesses of the benefits it could receive by helping the handicapped.

## New Designs and Guidelines for DD Aged Services

Our committee determined that protection and advocacy programs exist, but do not deal with the elderly developmentally disabled person. Therefore, the goal of this new design would be the development and implementation of an advocacy program for older, develomentally disabled persons. The objectives of this new design would include: (1) identifying needs; (2) developing a plan for implementation; and (3) actual implementation of the plan. The methodology for Objective #1 would be: (1) the development of a coordinating group for identification of needs; and (2) a survey process developed for resources performed by a coordinating group. Methodology for Objective #2 would include: (1) analysis of the data; (2) identification of existing resources; (3) identification of gaps in resources; (4) prioritization of service needs; (5) development of a plan; and (6) cost association. Methodology for Objective #3 would include: (1) search for funding resources; (2) resource commitment; (3) operational structure and funding; (4) training to include inservice programs; (5) public education; (6) local political support; (7) state plan inclusion; (8) inter-agency coordination with all state agencies; and (9) recruitment of advocates. An evaluation system could be developed to assess Objectives #1, 2, and 3.

Evaluation

1. Assessment of Objectives #1, 2, and 3.
2. Objectives (see chart next page)

| OBJECTIVES | Date Set | Date Met | Evaluation | Comments |
|---|---|---|---|---|
| I. Identifying needs | 6/7/78 | | | Coordinating Committee Established |
| | 6/14/78 | | | Coordinating Committee Meeting |
| II. Developing a plan | 6/21/78 | | | Survey Review Received |
| | 6/21/78 | | | Identification Resources |
| | 6/28/78 | | | Identification Service Gaps |
| | 7/5/78 | | | Prioritize Needs Cost Identification |
| | 7/12/78 | | | Plan Development |
| III. Implementing the plan | 7/14/78 | | | Identification Funding; Place Plan in Developmental Disabilities State Plan |
| | 7/15/78 | | | Identification Tasks Recourse, Commitment and Staff |
| | | | | Tie Into Existing Systems |
| | | | | Joint Coordinating Committee Meeting |
| | 7/16/78 | | | Development of Plan for Mass Media |
| | | 7/16/78 | | Contact Local Politicians for Support |
| | | 9/30/78 | | Notification of funding Approved |
| | | 10/1/78 | | Implementation and Recruitment |

# Proposed Budget for New Model

## I. Professional Staff

| | | |
|---|---|---|
| Advocacy Coordinator | $18,000 | |
| Training Coordinator | 16,000 | |
| Secretary | 6,000 | |
| | | $40,000 |

### Support Staff

30 Volunteers

## II. Administrative Costs

| | | |
|---|---|---|
| Office, paper | $20,000 | |
| Educational materials | 8,000 | |
| Training materials | 15,000 | |
| Travel and per diem | 5,000 | |
| Staff development | 1,000 | |
| Consultation Fees | 2,000 | |
| | | $51,000 |
| | | ------ |
| Grand total for first year budget | | $91,000 |
| | | ====== |

WORKSHOPS III & IV
Workgroup 3
Group Leader: Edgar Pye
Group Reporter: Betty Hedgeman

Group 3 examined the area of financial assistance. Through a very interesting process of interaction, a list of the following 17 obstacles was established as follows:

1. Disincentives to employment.
2. Systems rigidity prevents mobility by client to move toward independence.
3. Regulations which perpetuate dependency and poverty, and dehumanizing.
4. Systems are not consistent in philosophy and goals, i.e., rehabilitation.
5. Personnel relating to financial planning for Adult Developmentally Disabled (ADD), are not trained for the assignment.
6. Exclusion of ADD from eligibility for some private support systems, i.e., insurance.
7. Systems regulations prevent meeting the client at point of need.
8. Assumption that the ADD is an indigent population and should remain so.
9. Lack of societal recognition that ADD population will require appropriate support including financial for entire life cycle, regardless of family financial status.
10. Funding regulations prevent long term planning for clients.
11. No valid assessment is being used by the government in determining time costs of financial support for individuals or service programs.
12. Needs assessment data has been ignored on all levels and has not generated the money needed.
13. Lack of existing financial resources for mandated services by client and family.

14. Lack of responsiveness on state level to utilize finanfinancial resources on behalf of clients.

15. Special interest groups within ADD population perpetuates fragmentation of funding to programs which impact on individuals in need of service.

16. Conflicting state, Federal, local regulations prevent and inhibit the money flow to client.

17. Separate funding/states agencies/goals and objectives related to mentally retarded developmentally disabled; aging programs do not encourage cooperative planning and funding for the agency serving the mentally retarded developmentally disabled client.

The group was then given the assignment of creating a model program of financial assistance. It was quickly agreed that the current system was inadequate and that a whole new system should be legislated. Realizing that that was probably not possible, it was decided to design a model of service delivery in which the money would follow the client rather than the program.

The model would include:

1. Funding the individual aging developmentally disabled and not any specific program.

2. Funding based on evaluation and assessment of the individual client's needs with the client or client representative's input and consent.

3. Following the belief that:

   a. the client receive basic maintenance for life;
   b. all health care -- medical and dental care be provided; and
   c. program support, such as vocational, recreational, or day treatment services be provided.

We therefore recommended that current legislation, regulations, and issues be amended so that:

1. all ADD have a guaranteed income;

2. all ADD have a health and dental care program at a funding level enabling them to purchase service; and

3. if employed, participation in the health services is not diminished but the level of guaranteed income is adjusted (a formula should be established).

For sake of reality, it was decided to recommend changes in what exists. In order to accomplish these recommendations, we took the 17 obstacles and categorized items under the following headings for recommended action. Legislative changes, regulation changes, community changes, and professional training and educational changes will be required.

Legislative Changes

1. New legislation is needed to allow a state to waive con-conflicting regulations which inhibit delivery of service to the ADD. Refer to Federal interdepartmental task force for action.
2. Amend legislation so as to guarantee income support for life for persons diagnosed as ADD.
3. Amend Medicare-Medicaid legislation and regulations to guarantee lifetime support for health care.
4. Amend appropriate legislation to authorize incentives for employment for ADD thus eliminating the disincentives which currently exist.
5. Legislation specifically aimed at cost effectiveness which should be implemented by the Health Care Financial Administration.

Regulation Changes

1. Regulations which implement legislation relating to ADD should be reviewed and amended in insure appropriate service.
2. Recommend to National DD Council that it assume responsibility to review all regulations impacting on ADD and make recommendations for legislation or regulation change and so inform the public.

Community Changes

1. To insure commitment toward financial support on the part of the community by developing awareness, acceptance, and involvement.

2. The development and strengthening of coalition efforts to avoid the fragmentation of funding.

### Professional Training and Education Changes

1. Appropriate training be provided to personnel relating to financial planning of ADD and money or financial support be provided to maintain those positions.

WORKSHOPS III & IV
Workgroup 4
Group Leader: Muriel Rose
Group Reporters: Carol McKy & Jeannie Garland

Our Workgroup focused on housing and counseling.

## Definition of Housing

HOME is the natural family, extended family, or foster family.

ALTERNATIVE LIVING ARRANGEMENTS (Least restrictive) are apartments, low-income housing, group homes, and 1/2 & 3/4 houses.

INSTITUTIONS are nursing homes, proprietary/non-profit, church, state, and private.

The group recognized the relationship between housing, finances, and transportation which are being addressed in other groups.

The primary goal is to have an array of housing alternatives which will meet the basic living needs of all developmentally disabled persons, aged and otherwise, according to their individual needs.

## Barriers to Providing an Array of Housing Alternatives

The two most difficult barriers are the zoning restrictions at the local level and the architectural barriers found in the structures themselves.

Of prime importance as a barrier is lack of an assessment of the housing needs of this population and a need to inform generic agencies, as well as the general public, regarding these housing needs.

Even when the array of housing is available, support services may not be available in the community (i.e., medical delivery system, day programs, recreational pursuits, and transportation).

Often minimal physical plant and programmatic standards are not met and/or enforced (i.e., life safety codes, chemical restraints, physical restraints, and respect for rights and responsibilities for each resident).

The reverse problem is the need to simplify the standards and allow choices as the alternative living arrangement becomes less restrictive.

Another barrier is that state and local funding sources often are a disincentive to the development of alternative living arrangements. The thinking goes, "Keep everyone together and don't contaminate the rest of us."

Methods to Implement Housing Alternatives

The group suggested the folowing methods to implement the proposed array of housing alternatives:

Step One is to determine the person and the agency presently responsible for the least restrictive housing needs for those aging developmentally disabled within each state. These may include:

1) The governor;
2) Central licensing agency;
3) Administrative agencies responsible for lifelong care of substantially handicapped persons;
4) Guardianship and protective placement agencies; and
5) Advocacy agencies.

Step Two is to delegate tasks to the state developmental disabilities planning council:

1) Do a needs assessment of what is available in the state. As part of the needs assessment the following support services must be coordinated:

a) treatment;

b) individual treatment plans; and

c) a unified and coordinated system to get services to homebound as well as the mobile population.

2) Ask for consumer input.

3) In light of the above results, plan and implement a strategy to develop that which is missing. Monitoring methods must be included in the plan.

4) Investigate the implementation of "late intervention" under the outpatient section of Title XIX.

Step Three is joint development of the economics of providing appropriate housing for the aging developmentally disabled population. Develop a fact sheet stressing that for those without nursing needs, nursing home care is very expensive. This will provide "teeth" for legislation.

Step Four is to encourage cooperative efforts between agencies addressing the needs of elderly and developmentally disabled adults.

The workgroup also discussed problems related to zoning. It was recommended that state zoning laws be developed to supercede local laws. Sixteen states now have state laws. Six passed them this year: Arizona, Wisconsin, Vermont, Tennesee, South Carolina, and Maryland. Four states have laws pending: New Jersey, New York, Pennsylvania, and Florida.

## Counseling

A helping relationship which can take place between two individuals and in groups at home and out of the home. This helping assists in the adjustment to the problems of daily living and in making appropriate choices.

Goals of Counseling

To assist the individual in better utilization of his own resources in the coping and adaptive skills, recognizing there is no one way.

Impediments

Personnel who are frequently asked to work with extremely large case loads. The lack of training indicates a very real need for inservice training.

A problem of interdisciplinary communication which is indicated by "turfdom" or staking out of territory. This "turfdom" can lead to the use of confidentiality as a smoke screen. It is difficult for professionals to recognize the rights of the person to refuse services. There is always debate as to who is qualified to provide services. There is difficulty in coordination and integration of information between providers.

Because of time constraints, this group decided to concentrate on housing and methods to reach its goals of providing the least restrictive housing.

WORKSHOPS III & IV
Workgroup 5
Group Leader: Irv Segal
Group Reporter: Lee Kallstrom

Members of Group 5 represented a wide variety of professional expertise from quite different locales and environments. This diversity greatly added to insights developed throughout the sessions. The charge to the group was to discuss and develop guidelines for the future of: transportation and respite care needs for the aging/developmentally disabled person. It was recognized that great emphasis has been placed nationally on the transportation issue as well as some aspects of respite care (and/or service). With this in mind, the transcript which follows summarizes concerns and considerations which were expressed, described and discussed.

## Transportation

An extensive range of available facilities and planned development of transportation systems exists from state to state and community to community. These differences prescribe a variety of different needs from one community environment to another. The range includes states having mass transits with "lifts" as an integral part of their community transportation system to states having no public transportation at all. Also represented in the latter are the small communities located great distances from any available service resources.

Transportation needs for the aging developmentally disabled persons go beyond just a wheelchair lift or access. Some of the expressed needs which exist somewhat universally and which require increased attention are:

1) Identification and education of the potential aging/developmentally disabled consumer and his family. This need is viewed as the first imperative. Many individuals are unaware of existing facilities, and more important do not know how to use systems which are available. Also, existing systems are often directed toward only one group of individuals. Lack of public relations may be a deterrent to more extensive use by many aging, developmentally disabled persons.

2) Education of professionals responsible for transportation systems with regard to specific needs of the aging/developmentally disabled. Included are program and schedule administration, vehicle drivers, and personnel who might offer assistance or provide special attention during travel time.

3) Coordination and cooperation between agencies to attain maximum usage of availble facilities. Often there is restricted use of vehicles and facilities due to ownership, contract restrictions, or populations designated for specific inclusion. Scheduling is often restricted to a five-day week. Provisions for the individual to engage in personal travel for shopping, recreation, or attendance or worship services on weekends are needed in many communities. Coordination of existing facilities as well as proposed additions must be developed in accordance with the stated needs of the potential customers.

4) Individual privileges regarding personal transportation also vary from state to state. Driver manuals designed specifically for the aging/developmentally disabled are available in some states while in other states no provision is made to allow these

individuals to drive at all.

5) Finally, the potential consumer must be found and questioned regarding how he or she might use a system, and what type of specific special needs exist or might arise. The comprehensive development of the system should be based upon the incorporation of these needs.

A model system of transportation is seen as one with the least restrictions. It should be a coordinated system making use of facilities that are available or proposed.

## Respite Care

The membership of the workshop submitted the following as a working definition of respite care following a great deal of consideration and discussion: "Respite care encompasses a temporary period of relief of chronic responsibility. There are primary and secondary consumers, that is, the aging developmentally disabled individual and members of his family, parents, and others involved with that individual's well being." A wide range of care services could be included under this definition, including homemaking assistance, back-up support from community and neighbors, the provisions for vacation and/or leisure time, etc. Specific descriptions and definitions of needs should be provided by the primary or secondary consumer.

Due to the nature and scope of possible respite care services, the general model for service delivery must remain in the cultural, social and ethnic mores and ethics of the particular consumer.

Presently, some of the perceived needs which might enhance the value of the model are:

1) Funding in many areas and regions.

2) Improved use of existing systems, facilities, and agencies. This might be increased by more extensive education of both professional service providers, as well as the potential consumer. In some situations, specific training for personnel in existing agencies must be provided. These agencies might include day programs, visiting nurses, homemaker assistance, public health nurses, and Big Brothers.

3) There is need to develop consistent terminology for better communication at the national level.

4) There is need for recognition of other secondary or "back-up systems" which might be described as "community networks" and which might include churches, extended families, neighbors, etc.

The thrust of future development should be oriented toward community development, utilizing professionals to act as advisors to investigate the specific community needs in any particular setting. Consumer input into the development at all levels should be imperative. The cost of any such program would be determined largely by the community in question and the perceived needs of the consumer.

## WORKSHOPS III & IV

Workgroup 6
Group Leader: Bob Heft
Group Reporter: Ethel Beal

Our group was assigned two service areas: information and referral, and education. The group's tasks, consistent with the assignments made to other groups was to discuss impediments to service provision during Workshop III and to develop models for service during Workshop IV. In general, we followed the suggested format; however, for continuity, activities of both workshops will be consolidated in reports of the two service needs addressed.

### Information and Referral: Impediments

An initial obstruction was the inability to confine our discussion to information and referral. From the outset, we expanded this service need to include coordination, counselling, information, referral, and follow along. As the workshop progressed, we struggled with a bad case of "lacks." We felt development of information and referral systems suffers from lack of leadership, funding, coordinating awareness of professionals, awareness of clients, visibility, accessibility, structure for linkage, and professional expertise.

We recognized that programs which are available are often fragmented, categorical, and turf oriented. It was observed "Because information and referral is the interface between clients and service it has tremendous potential which probably isn't used very well." More succinctly, another participant stated, "We have a pile of services which may or may not reach the consumer."

When we started looking at how consumers utilize the system we realized that for the aging/aged developmentally disabled individual there may be many practical and subtle impediments to systems use. These obstacles may range from the lack of comprehension about the system, to the inability to dial a telephone number, lack of speech, hearing problems, lack of writing skills, restrictions imposed by "caretakers," and inability to obtain or use transportation. From this perspective, we recognized the importance of a "significant other" in influencing the quality of life of the developmentally disabled individual.

The group agreed that the development of an information and referral systems is probably the responsibility of State Developmental Disabilities Councils. However, consensus indicated we had little confidence in the implementation skills or interest of State Development Disability Councils in providing meaningful programs. Most of the group indicated that the Councils which they had observed tended to be politically motivated, uninformed, inert and unable to exert leadership. It was suggested that possibly we may add to the problem since we have probably not exerted much leadership in changing the status quo.

During Workshop III we displayed an occasional tendency to pull away from thinking in terms of specialized information and referral systems for developmentally disabled individuals. Instead we proposed that a local area board should address itself to generic human needs. It was suggested that the focus should be on individuals needing services, rather than specific disabling conditions requiring alleviation.

As we started to develop our model, we recognized that the "operator" of the information and referral system needs to be experienced in inter-personal relationships, and will have to have an acute awareness of programs, activities and needs within communities. He/she will also have to have the ability to relate those needs to the community's social/cultural norms and to the clients' goals. Recognition must be given to individual and environmental variations, and there will probably be no "standard" solutions.

Depite our earlier discussion of generic information or referral systems, for expediency the development of our model was directed toward developmentally disabled adults, age 55 or older. Recognizing cost/effectiveness, efficacy, political, and legislative factors we developed a model using the existing structure available through Area Agencies on Aging.

## Education

Focusing on the discussion of "education" brought an awareness of how jargon can inhibit communication. As the only direct service provider in the group the recorder encountered the most difficulty in understanding what the term "education" entailed. (Most specialized agencies providing evaluation and habilitation services for developmentally disabled adults refer to their services as "developmental training." "Education" is something which the agency assumes is done by public schools, institutions, colleges, and universities. Fortunately, other members of the group were able to articulate "education" in terms of attainment of basic living skills and activities related to daily living.

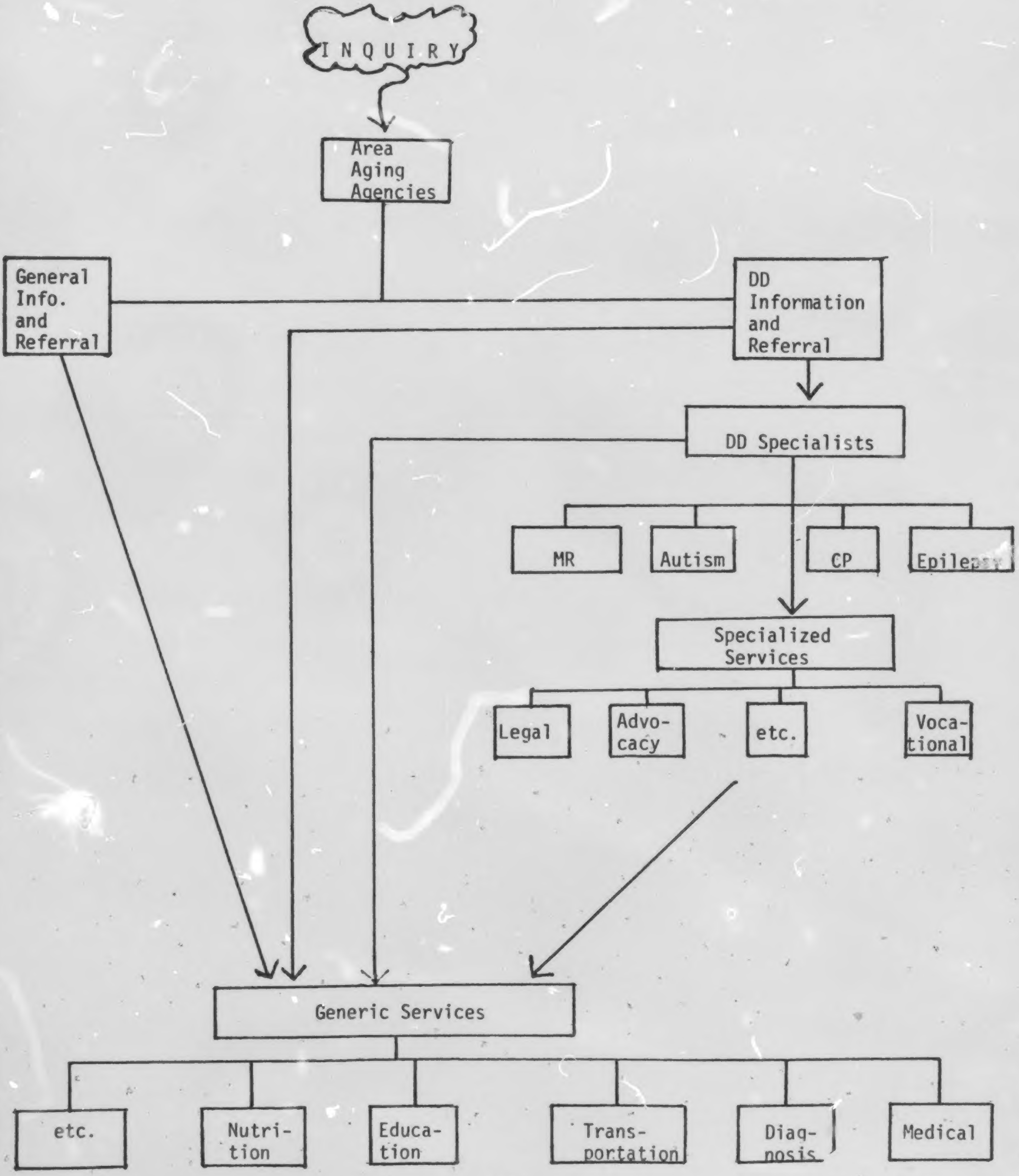
The discussion of impediments to service delivery was concerned mainly with the developmentally disabled individual, rather than the structure of services. We talked of the individual's lack of previous training and how the aging process itself might diminish the ability to acquire new skills. We commented on self concept and role expectation, particularly "the eternal child" image. We noted a tendency for this to affect the individual's growth since it decreases self expectancy and increases dependency. It also inhibits the individual's ability to relate appropriately or realistically to the various chronological/maturational stages of the life cycle.

Recognition was given to the need for more realistic goal planning involving the client.

When we looked at opportunities for "education" for the aging developmentally disabled adult, we felt there were not enough programs. Also, in many community programs (such as senior citizens programs) the developmentally disabled adult is subject to much discrimination because of his/her disability. In some programs they are denied services because of their age; therefore they become victims of multiple discrimination. It was mentioned that public awareness programs are not devoting enough attention to aging developmentally disabled persons. Consequently there is little understanding of their needs, and too little acceptance from the community as a whole, particularly from their "normal" peers and from all professionals.

Moving along to our assigned task, the group tried to relate our concerns into neat "boxes" and develop a flow chart similar to the information and referral model. We were using existing systems, and as the subject was "educational" we naturally itemized public schools, community colleges, and university affiliated facilities. We supplemented these with community developmental disability programs, state institutions, and state agencies. We struggled with our

## A MODEL SYSTEM FOR INFORMATION AND REFERRAL SERVICES FOR DD ADULTS AGE 55 AND OVER


INQUIRY
Area Aging Agencies
General Info. and Referral
DD Information and Referral
DD Specialists
MR
Autism
CP
Epilepsy
Specialized Services
Legal
Advocacy
etc.
Vocational
Generic Services
etc.
Nutrition
Education
Transportation
Diagnosis
Medical

boxes and labels, but no one was satisfied as our flow chart really did not "flow."

In futility, we discarded our rough model and returned to emphasis on the educational needs of the individual who is developmentally disabled. Agreement was reached on certain basics as follows:

1) Materials utilized and "groupings" should be age appropriate and "adult" oriented.
2) Recognizing the learning which occurs through exposure to various environments, instruction should take place away from individual's home environment.
3) Every model needs a component that provides opportunities for learning basic skills not previously acquired (for those with no previous exposure to "education"). There is a need for opportunities to increase skills; and, a component concentrating on retention of required skills. To summarize, the purposes of training should be remediation, habilitation, and maintenance.

We concluded we could not draw a flow chart to represent our educational model as individual needs cannot be expressed in terms of boxes, organizational structure, or labels. Rather, the educational model should be, as already recognized by PL 94-142, individualized prescriptive program planning.

# ISSUES CONCERNING THE DELIVERY OF SERVICES FOR THE AGING/AGED DEVELOPMENTALLY DISABLED PERSON FROM A NATIONAL PERSPECTIVE

# NATIONAL ASSOCIATION FOR RETARDED CITIZENS AND THE AGED DEVELOPMENTALLY DISABLED PERSON

John J. Pezzoli, ACSW

Chairman
Community Services Committee
National Association for Retarded Citizens
Arlington, Texas

I am happy to represent the National Association for Retarded Citizens (NARC) at this important conference. NARC, both the national board, committee and staff and the over 1500 state and local units and 300,000 members, clearly have an interest in the issue of aging and mental retardation. As the major consumer actional organization serving the mentally retarded it is appropriate that NARC participate in formulating recommendations to deal with this issue and we are grateful for the opportunity to do so.

It has often been noted by many long-term observers of NARC, that one can almost see in the concerns and activities of NARC the growth of a generation of retarded citizens. Almost as if a single generation of children had been addressed and followed, the priorities of the organization have gradually broadened over the years, first advocating principally for special education programs for children, then for vocational and residential services designed principally for adults. The change of our name from National Association for Retarded Children to Citizens in 1973 symbolized (some thought far too late) the maturation of our concerns and--figuratively--the maturation of a generation of children which NARC began serving in the early 1950s. Now we are urged to extend our concern farther, to include aged mentally retarded persons. Certainly it is not only proper to respond to the needs of all retarded persons that NARC address this issue, but it is also consistent with this "aging trend" of NARC activities

Another trend in NARC activity can be traced over the years and is relevant to this issue. Documented definitively by Wolf Wolfensberger at the 1972 Convention at Montreal in his paper "The Evolution of Voluntary Associations," is the trend of consumer action groups like NARC to move from being service providers through service obtaining to monitoring and advocacy. Another characteristic of the maturing voluntary association, according to Wolfensberger, is the generalization of concern first from individual retarded persons, to the retarded in general, and finally to all handicapped persons. This trend or characteristic is also noted in individual parent advocates and is the essence of collective voluntary action such as is represented by NARC. It is relevant here as NARC, which for years demonstrated and gave a vehicle for the broadening of concerns from individuals to concerns for the class of persons called retarded, and which already has forged a new cooperative spirit and experience with other major organizations representing other handicapping conditions, now forges a cooperative bond with the interests and advocates of the aging.

Mental retardation and aging have much in common as handicapping conditions--and much that is different. It would be very revealing to study carefully how public opinion perceives each. Superficially, at least, one would predict a response that one problem (mental retardation) is clearly seen as a problem and a handicap, while the other (aging or old age) is a "problem" only in the eyes of some and a handicap only for some. Aging is thus seen as a conditional handicap, a handicap which can be "prevented" by providing a supportive, adaptable environment or through the efforts of individuals. That would appear to distinguish it from mental retardation as a "problem." Of course, those familiar with the definition and nature of mental retardation realize all too well how environmentally relative mental retardation itself is. If the environment were more supportive, tolerant, helpful or cooperative, the adaptive behavior deficiencies of the retarded would be lessened as would, therefore, the handicap of mental retardation. Thus, mental retardation, like aging, may be seen as a conditional handicap, although certainly not to the same extent.

Mental retardation and old age are both handicaps in part because of social devaluation. The reasons for our contempt, fear and devaluation of both the mentally retarded and the aged (in spite of the fact that only early death prevents us all from eventually being aged) defy rational justification but call for study to describe--and perhaps mark for elimination--this dark side of our character.

A final area of comparison--and difference--is the similarity of senility (an awful term which quite imprecisely refers to what I am told is a gradual and selective loss of capacities among some aging persons, due apparently to an inexorable series of stroke-like cerebral "incidents," as Tennessee Williams called them) and mental retardation. Dramatically different in etiology and developmental implications, there are nonetheless some functional similarities between the behavior and needs of persons whose intellectual and adaptive capacity are impaired either late or early in their lives.

The combining of the two conditions--mental retardation and aging--is, of course, the subject of this conference. What are the problems of the mentally retarded old person? Are they unique problems?

To begin to answer those questions I have reviewed much literature on the problems of mental retardation and aging--much of it generated by the pioneering conferences sponsored by this University and the Institute for the Study of Mental Retardation and Related Disabilities. While many problems and a few new ideas seem to have been generated, my feeling is that no unique, distinguishing or particularly dramatic issues specific to the chemistry of combined mental retardation and aging have developed. I do not know much more about a problem called "Gerontological Aspects of Mental Retardation" as a result of my study, but I do know something more about mental retardation and a lot more about aging. The message I get is that we need to continue to strive to develop progressive, humane services which help people reach their fullest possible potential to live in the community of their choice in as normal and normative a manner as is possible given the individual's capacity and desires. This mouthful of a goal incorporates many active principles of progressive services and applies equally to the mentally retarded and to the aged. It also applies equally and not uniquely to the mentally retarded aged and I just don't see any mystery about the problem.

Certainly there is a problem for the mentally retarded aged person, however. There is a problem basically because we do not do nearly a good enough job now for either the retarded or the aged. Moreover, we seem to do a very bad job--or nothing at all--for older retarded citizens. This conference, its 1975 predecessor, and a scattering of other conferences (I attended one in Virginia in 1977) and programs around the country have done much to remind us that the older retarded citizen should receive sensitive, appropriate services in the community services movement now, rather than later or perhaps never.

From my vantage point as an administrator of a local system of services for retarded citizens and chairman of NARC's Community Services Committee, I am aware of certain other problems. Our previously stated concern about both the retarded and the aged is that they are groups which are both significantly and similarly devalued by society. The two groups thus share many of the same problems of societal indifference, stinginess, and contempt, mixed with equally dehumanizing pity, patronization, and--most annoyingly--a tendency to treat both retarded and aged persons as children. We tend to talk to both the retarded and the very old in the same manner we do to children, foreign visitors and TV Indians: in loud voices using simple words and with kind of a melody to our phrases.

In the last ten years two principles have emerged which offer promise of improving services for retarded and aged persons and an enlightenment of public attitudes toward these groups. These principles are the Developmental Model for services for the retarded (which holds simply that all persons are capable of continuous growth and should be helped to achieve this growth) and the principle of Normalization (which holds that culturally normative means should be utilized to help retarded persons live their lives in as culturally normative a manner as possible, thus minimizing their deviance and isolation from the community).

These principles have led the way in developing a system of community-based services in the past 10 years. (Along the way some damage may have been done to the concepts as the dogmatic and the naive tended to distort normalization into a belief or crusade that we could "make the retarded normal" at the same time that they exaggerated and misunderstood the concept of maximizing development, suggesting implicitly that we could change a profoundly retarded person into a mildly retarded person if we tried hard enough.) But the time for excesses of rhetoric and dazzling promises has passed and the true test of the concepts--joined by the resulting movement forward of the community-rased service model--is taking place.

Though the National Association for Retarded Citizens would be the first to say that not enough progress has been seen, there are in some places enough experienced and reasonably fleshed-out systems of community services to afford a solid demonstration of the effectiveness of these concepts and community services. The spark struck almost a decade ago has been nurtured and has grown.

Our system of community services as an alternative to institutions is rather young. It is also heavily biased toward the young. It has emphasized developmental services in a sharply drawn contrast with institutional services, but, apparently, only for the young. Perhaps partially explaining the vigor, idealism and focus on youth of the developing community system (and its corresponding ignorance of the aging retarded) is the fact that the community service system is predominantly led and run by very young people. Furthermore, the system has naturally begun with what were thought to be relatively easier problems. Thus there has been a bias toward mildly retarded children and young adults as initial clients in developing programs. Older retarded persons either remain in the institution or, if in the community, unrecognized. Again the older retarded citizen is ignored. The choice of program goals and activities in community programs is also weighted toward the young. The developmental tasks chosen for training are usually those characteristic of young adults, such vocation acquisition, sex education, and independent apartment living. While it is true that older adults are capable of continued growth and development, the vast majority of community program goals and activities are simply not age appropriate to older clients. In fact, it is only relatively recently that we have become sensitized to the developmental potential and needs of older persons at all, and this sensitivity has come through advocacy and arguments quite similar to those used in the mental retardation field to convince people that retarded children were capable and desirous of growth. Clearly, community service programs assign low priority to the needs of older retarded persons, even to the point of failing to recognize their needs.

A major goal and focus of current developmental programs is independence, or near independence. Consideration of age appropriate normative patterns of older citizens and a realistic assessment of their capacity and needs may advise against the single-minded pursuit of independence as a goal for services for the elderly. Certainly we wish to reduce dependence and helplessness, but a positive interdependence, a sense of community and friendship, and a supportive environment may be more appropriate service goals for both the aged and the retarded.

Many signs point to the need to improve our knowledge and sensitivity with regard to aged retarded persons. Dr. Robert Segal's paper, "Trends in Services for the Aged Mentally Retarded," suggests that improved medical care and generally safer living conditions for the mentally retarded mean that more mentally retarded persons will live to advanced age. This population, therefore, will be larger and need a bigger slice of the service pie in the future. Segal also points out that increased advocacy by and for the aged means that we will have to become more responsive. Certainly, this conference adds further impetus. I would add that the natural evolution of community programs also contributes to the expectation that services for the aged retarded person will soon improve. Looking at the current system of services as a beachhead, the need and natural expectation now is that the community-based forces will dig in, consolidate their positions and begin broadening their coverage to include harder-to-serve clients, including the aged.

NARC can and should play a role in this effort. Having been a major leader in the advance for rights and services for retarded citizens, it is fitting that NARC should always offer leadership and assistance at the cutting edge of that continuing advance. The needs of aging mentally retarded persons calls for NARC action in 10 areas, each of which displays an important NARC role. However, to have effect, these initiatives must be shared by all who are concerned about either the aging or the mentally retarded:

(1) Advocate -- NARC has been the principal and leading advocate for the rights, needs, and interests of retarded citizens. NARC advocacy should explicitly include the needs of older retarded

persons. Also, NARC and local ARCs are the major sponsors of Citizen Advocacy--a one-to-one volunteer advocacy program which would directly respond to many of the needs of individual retarded/aged persons.

(2) Consumer involvement/action -- NARC is led by consumers or surrogate consumers in the form of parents and friends of retarded persons. Moreover, more and more local ARCs are finding ways to help involve retarded persons directly in meaningful consumer roles. Clearly, NARC needs to involve and seek the input of older retarded persons and their advocates or representatives. Cross representation between aging and mental retardation advocacy groups would be useful.

(3) Public education -- Doubtless this conference has amply documented the need for public education. NARC is very good at public education at both the national and community levels. We should make sure NARC's message is broad enough to inform the public about the needs of all retarded persons--regardless of age. Because negative attitudes exist toward both aging and retardation, this job will be difficult.

(4) Innovator/demonstrator -- NARC, and particularly local and state ARCs, are experienced and credible innovators and demonstrators of novel or progressive new services and techniques. Current and past ARC efforts in this area should be identified and highlighted, and new research and service proposals should be developed, funded and evaluated.

(5) Monitor/evaluator -- A role for all levels of ARCs--national, state and local--has been to continuously monitor and evaluate services for the mentally retarded. The plight of aged retarded persons--particularly those languishing on institutional back wards and

in bad nursing homes must be determined and our attention drawn. ARCs must broaden their concerns and include monitoring of nursing homes and other services to the aged, in which unrecognized aged retarded persons may now be grossly underserved and totally unrepresented.

(6) Researcher -- All levels of NARC support research and some conduct important research. Clearly much more research about the problems of aging and mental retardation is essential and NARC can and should encourage investigation of needs in this area.

(7) Prevention -- ARCs have led the way in introducing preventive measures. The problem of mental retardation--and with it the problem of aging/mental retardation--can and must be drastically reduced. The references to PCMR's and President Nixon's pledge to reduce mental retardation by half by the year 2000 are sounding emptier now and will be nonsense soon if dramatic progress is not urged now.

(8) Cure -- NARC introduced in 1977 the concept of cure--an introduction not without controversy. Exciting biolgocial and neurological research promise much for the not-too-distant future. Equally exciting are modern-day "fountains of youth"--new research suggesting ways to limit the debilitating, degenerative effects of advanced age.

(9) Coordinator -- NARC often serves as an important organizer or coordinator of issues concerning all handicaps. NARC should extend its horizons of concern beyond even the general notion of "handicap" and become actively involved with appropriate organizations serving the aged to form a cooperative, united front on this issue.

(10) Volunteers -- NARC at all levels is volunteer-led and volunteer-activated. There is a need for volunteer action in this area. NARC volunteers should get involved with aging retarded persons. NARC should get other volunteers involved. Last but not least, we can ask how many aging retarded persons get to be grandparents? NARC—or some other organization--should reverse the Foster Grandparent Program and let retarded old folks have a chance to bounce kids on their knees. That's normalization!

# RISING EXPECTATIONS FOR PARTNERSHIP WITH THE ADULT WHO IS AGING AND MULTIHANDICAPPED

Carol Murphy, ACSW

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## Introduction

The United Cerebral Palsy Association (UCPA) was founded by parents of children with cerebral palsy in 1949 and has retained its family centered character. The major focus in the past was provision of needed medical, educational and recreational services, both home-based and center based, with ongoing parental support. With the impact of Public Law 94.142 promising a public education for all handicapped children, UCPA has been able to direct its energies towards prevention, early detection, and services to the 0 to 3 year old and to focus on the specialized needs of teens and adults. My concern and your concern today is with these adults. Where are they now and where are they going? Is there a future for the aging person with cerebral palsy?

## Background Information

We are faced with a generation of adult consumers who tell us they have spent the majority of their lives getting fixed and molded and shaped to approach the norm more closely; what they really needed was the sense of "I." Who am I? Can I make friends? Am I loveable? Can I be a productive member of society? Am I only the object of a series of ministrations or can I control and manage my own life? UCPA is attempting to put the consumer in the driver's seat to emphasize personality development and differentiation of self as the important thing with any necessary therapy or interventions forming a support to this goal.

In many ways the stereotype of the multihandicapped person fits the age-old stereotype of "elderly" that expects to see a person who is asexual, child-like, dependent, unable to make decisions, lacking interest in surroundings and non-productive. This person may live at home, depending on parents for all needs, with little or no interaction with the community. Peer relationships are minimal and often the passage from childhood to teens to adulthood is hampered by inappropriate expectations which continuously cast the individual into the role of a child.

The older individual in the institution often has been lost in a system where cognitive needs are overlooked as bodily needs are met. One could question how it is possible to deliver effective service if consumers have no choice of service or representation in the evolution of service. This problem is compounded when consumers are non-verbal, multihandicapped and dependent upon staff for meeting a major portion of their daily needs (Boles & Bible, 1976).

With the ongoing emphasis on deinstitutionalization, many consumers are being moved to nursing homes. Here residents are cast in the sick role. Design of routine and programs are geared to personnel efficiency, safety regulations and economic considerations, rather than to the social-emotional needs of the residents. One must abide by a schedule, get permission to leave or have company, eat at a specified time a meal that has planned and chosen by someone else, and dine with a group of individuals who happen to be there (Sieg, 1977).

In each of these situations, all risk is removed, few choices are necessary. Docility is rewarded and any attempt to show anger or frustration is termed an emotional outburst, confirming the initial need for dependency and structure. The big lie is being continuously reaffirmed--"I am not as good as the average person." And in most instances, the placement is seen as a permanent solution. He or she will never be able to make it on his own.

Many of you have probably heard, as I have, the parental remark, "I hope he dies before I do because no one else would be able to care for him like he's cared for at home." Do we wonder where the apathy and lack of motivation comes from on the part of the individuals involved? In his book Culture Against Man, Henry tells us that "primitive people imagine that the soul leaves the body at or just prior to death but in our institutions for the aged, obsolete human beings are detached from themselves long before they are lowered into the grave." (Sieg, 1977). Should we be surprised then to know that the cerebral palsied persons often in their teens and 20s have been mainstreamed into the worst tradition of services to the elderly, and, like many of them, are living in bodies that refuse to die when in spirit they have given up all hope of living. Gerontologists and the aging themselves are demanding alternatives to institutional and nursing home care. The developmentally disabled can speak from experience to indicate that there must be a better way.

Some theories on aging stress remaining active as a necessity for aging successfully. Others say a disengagement process takes place, wherein people withdraw their emotional investment from objects, persons, and places and that they redirect their energy from outside to inside with a diminished sense of responsibility for external matters. Another view agrees that both are possible and suggests a personality continuity theory. Individual variations in later life are explained developmentally which means that one's behavior in later life is a continuation of that which is seen earlier. In this sense, aging is seen as a further unfolding of one's personality (Sieg, 1977). If this is the case, it would seem that personality development to its fullest potential is the best insurance for successful aging for the developmentally disabled. Since persons with developmental disabilities have not had the number of accumulated experiences of their able-bodied peers, this task becomes more complex, and a challenge to organizations like the United Cerebral Palsy Association.

A prominent physician in the field of developmental disabilities made a casual remark to me recently which I think presents a philosophical question. We had just participated in a meeting with a mildly involved individual with cerebral palsy who was out of work despite two masters degrees. The physician said, "How can we expect to help a multihandicapped individual with all kinds of complex problems, when we can't even find jobs for the mildly involved college educated person?" This was not the remark of a callous unconcerned person, but a remark which may express the unspoken frustration of many people with the dilemma of allocation of time and resources. How do we handle the cost effective question raised on every side by community, government and local board members who may question, for example, the high price tag on service delivery in rural areas or service to the person who is multiply handicapped?

## UCPA Initiatives

UCPA is taking a hard look at this. We have assumed the role of developing some national models and using our resources to meet the challenge of the individual with cerebral palsy who requires a complex service support system in order to live with dignity. Some key areas of involvement with adults are advocacy, housing, and employment.

1. Advocacy. A five-year demonstration project on systems advocacy funded jointly by the Bureau of Education for the Handicapped, and National Institute of Mental Health, and the Developmental Disabilities Office is particularly appropriate to the concerns we have today. Five UCPA affiliates were selected for the project based on differences in population, geography, levels of government, patterns of service availability and organizational patterns and programs. Project outcomes indicate the need for a systems approach to change. This approach makes it possible to act on the structural barriers endemic in the physical environment, institutions, social policy and the complex service delivery system. The thrust of the national organization is to go beyond the provision of services to provide a locus for an identifiable advocacy function--to be a catalyst and agent for change. Experience with the Advocacy Project tells us that advocacy does not just happen; it needs to be a planned and a systematic effort designed to change attitudes and myths about persons with cerebral palsy as well as seeing that his legal and human rights are met. Specific examples of advocacy models can be found in the publication Thinking, Learning, Doing Advocacy, a report on the National Advocacy Project available through UCPA (Dickman, 1976).

2. Housing. In its evolving expertise in the areas of housing for the multiply handicapped, UCPA provides consultation on: (a) housing which reflects the individual's choice and least restrictive alternative: (b) housing which blends in with the surrounding neighborhood; (c) housing which is financially secure; and (4) housing which has available a system of support services including consideration of transportation to community resources.

When attendant care is needed, we think it is preferable for the individual to be the employer to insure the fixing of responsibility with the individual to manage his own life. Group living arrangements may be more appropriate when they reflect the person's choice of lifestyle rather than an agency or institution's training approach to independent living. It is easy to document instances wherein this would be impossible, yet I think we can err more heavily when our conceptual framework does not stretch far enough to allow for individual abilities which may exceed our expectations.

There are a number of excellent models for independent living programs throughout the country. In 1974, UCPA of Pittsburgh procured an H.E.W. demonstration grant entitled "Developing Opportunities in Individual Responsibility (DOIR)." This grant provided three major services: (a) a counselor-advocate to define the housing difficulties encountered by disabled persons and to help seek out solutions; (b) monies for special adaptations to modify or equip apartments or homes, making them accessible to and usable by physically handicapped persons; and (c) transportation to permit individuals to reach necessary services in the community.

In addition, a supervised apartment project has been developed in cooperation with Allegheny County. The site selected for this project is a privately owned housing development of 285 garden apartments. The local housing authority had arranged to use 85 of these townhouse apartments for public housing purposes and agreed to set aside five units for UCPA clientele. Each disabled resident signs his own lease with the Pittsburgh Housing Authority and the rental cost is calculated on a sliding scale schedule which is appropriate to each consumer's monthly income. Four of these two-bedroom apartments serve as the residences for eight consumers. The fifth apartment is an office and residence for support staff. Fifty percent of the residents are in wheelchairs. Half of the residents are from the community and the remainder are from state institutions or intermediate care facilities. All apartments have been completely adapted with such devices as grab bars, ramps, stairway lifts, and heat and pressure controlled shower devices.

It is apparent that new approaches will eventually mean the demise of the large institutions which do not provide optimal opportunities even for the profoundly handicapped. One proof of this assumption is the experience of UCPA of New York State, which started a facility for the most catastrophically disabled in a small rehabilitative care center. In June 1976, 49 residents who were selected by a state institution as being the most profoundly disabled both physically and mentally were referred to this new program. The chronological ages ranged from 20 to 38 years. The duration of stay in the state institution was from 18 to 33 years. When the residents entered the new program, they were in "cripple carts," and were "bird fed," that is, fed pureed food in supine position. None were toilet trained. Active programs were planned and implemented for each person. Fourteen are now ambulatory, 20 are able to get around in wheelchairs, 19 are fully toilet trained, 22 are presently in toilet training programs, 27 are self-feeders, 13 are in feeding programs, eight attend community workshops and three are living in their own apartment. The staff is highly motivated and the morale is excellent (Weinrich, 1977).

3. Employment. In Wichita, Kansas, at Center Industries Corporation, persons who are severely handicapped work alongside able-bodied persons in the manufacture of a variety of products including the contract for license plates for the state of Kansas.

This was made possible by a unique coalition of efforts and funding sources involving United Cerebral Palsy Association of Kansas, Wichita State College of Engineering, Kansas State Department of Vocational Rehabilitation, and Small Business Administration.

Center Industries Corporation was founded and an accessible 26,000 square foot manufacturing plant was built. The engineering component provided the link between the person and the machine and UCPA supplied back-up support services in areas of job training, residential apartments and transportation. Seventy-five percent of the work force was disabled. All received the minimum wage or above.

Another project sponsored by UCPA of Kansas City is TALL--Training Alternative for Living and Learning. Funding comes from Comprehensive Employment & Training Act (CETA) and HEW. The project attempts to get the involvement of the employing company at the outset, finding out specifically what it needs, and matching a person to the job. The project provides assessment and training for the individual and claims that the bulk of the four-month stay in the program is spent on behavior and interpersonal relationships. The shortest amount of time is needed for skill training. The average cost for a job site modification is only $30.

### Future Directions

1. *Education and Training*. One of the most probable reasons for the lack of success in preparing the person with a developmental disability for life in the community is that most training environments are not natural. They fail to offer the expectations, survival skills, and resources which real life situations demand. Even the highest quality education in an institution does not provide the skills needed for adjustment to life in any other special environment (Lent, 1976). Living in an institution prepares a person for life in an institution. Living in a group home prepares a person for life in a group home. Immersion in the real life circumstances, with props supplied as needed, may accomplish the goal of independent living in far less time and trauma. This may also hold true for the workplace, where persons receive training for a specific job known to be in demand, rather than spending years preparing for jobs which may not exist.

On another level, training is needed which will allow for a transdisciplinary approach for staff involved with working in aging programs, developmental disability programs, and adult special education programs. There are numerous federally funded adult education programs, but these programs have not been utilized anywhere near capacity by people in the developmental disability field. The programs with the least federal support are clearly recreation and social development areas, areas which become increasingly important to the aging developmentally disabled person (Ross, 1977).

2. Bio-engineering. We are approaching a real breakthrough in the communications field and in the area of bio-engineering. Prototypes now in the experimental stage are showing remarkable results. For example, we now have technology which enables the non-verbal individual to use a computerized voice. We need a stable funding source to provide the technical expertise of specialists and a policy which makes available to the individual the equipment needed. A 1977 report of the House Committee on Science and Technology concluded that the efforts of the principal federal research programs in the area of rehabilitation technology are small, fragmented, uncoordinated, without any consistent set of priorities, and not broadly disseminated. The most frustrating conclusion of the report was that "the development effort ceases when the technical research is completed, and its potential application is either neglected or fails to materialize because the research did not start with a sound handicap oriented goal or there are no distribution means." Needless to say, this whole area is one of UCPA's priorities for 1978.

3. Medical Needs. Medical needs of the developmentally disabled are often overlooked. Persons with cerebral palsy have spent years receiving orthopedic and neurological services as children and are usually not seen when they reach adulthood. Physicians are hesitant to treat the medical needs because they believe that treatment of cerebral palsy belongs to one of the medical specialties. Programs need to be developed which address this issue in the local community, in medical and nursing schools, in university curricula

including such programs as dentistry, nutrition, and physical, occupational, and speech therapy.

As a person ages, medical needs change. For example, an older multi-handicapped individual who once could operate a regular wheelchair may have developed a need for a motorized one and other assistive devices not previously required. It is precisely when these items are most needed that they are most likely to be denied because of the hesitancy of our culture to invest in its aging population. A report on handicapped aging at the White House Conference on the Handicapped (Davis & Onyemelukwe, 1977) states that the handicapped aging are grouped in with the able-bodied elderly. Although advocacy groups use this fact as a tactic to convince lawmakers to approve funds, in the final distribution of funds, the specific needs of the impaired elderly are not addressed (Davis & Onyemelukwe, 1977). Within this minority of impaired elderly are a smaller minority of developmentally disability elderly. Turf problems between major groups and sub-groups need to be worked out cooperatively. Instead of vying between groups for the limited monies available, coalition efforts need to be encouraged to create the necessary impetus for making the overall funding more substantial.

All this implies a need for massive breakdown of attitudinal barriers. On the one hand, for example, we have persons with handicaps demanding inclusion in the nutrition programs for the elderly. On the other hand, we have individuals with handicaps asking and getting from HUD a separate housing office since they objected to being linked with the elderly. Options for choice should be available.

In the legislative arena, UCPA is actively seeking expansion of federal home health service benefits and requesting that special consideration be given to the financing of attendant care as a home health service.

UCPA is also actively participating in dialogues on national health security proposals.

## Conclusion

UCPA [illegible] encouraging all its affiliates who give direct service to become involved in an accreditation process. We believe this is our best way to assure on-going evaluation, accountability, quality of program, and attention to umet needs in the comunity.

We see the role of many affiliates changing from providing an in-house service to becoming the packaging agent which pulls together the necessary support services from various community and governmental resources to enable the individual to live in the community.

With growing access to mandated governmental programs, UCPA's role will be to continue to serve as a monitor of quality programs, to assure individual entitlements, and as an advocate for systems change. With the increase in medical knowledge of prevention and the subsequent decline in the incidence of cerebral palsy already forecast, the bulk of research and program emphasis will shift to the perfection of bio-engineering, communication technology, and behavioral science research which should be of great help to the multi-handicapped aging adult.

Meeting the heightened expectations of today's adult consumer has had a large part in creating the rising expectations of United Cerebral Palsy Association. It is only through multiple coalitions on many levels that this goal can be achieved.

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# DEVELOPMENTAL DISABILITIES AND GERONTOLOGY FROM THE EPILEPSY PERSPECTIVE

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The Epilepsy Foundation of America is pleased to be a part of this important conference focusing upon the needs of the elderly developmentally disabled. Far too many years have passed during which the aged population has been neglected and ignored. This is especially true of the population we are addressing today.

A report was issued last August by the National Commission for the Control of Epilepsy and Its Consequences which was mandated by Congress. It is a comprehensive, in depth study of the problem areas, the needs and recommendations for meeting those needs. However, the commission did not specifically address the issue of the aged. In studying the commission report, however, one quickly realizes that a majority of the service needs addressed apply directly or indirectly to the population that we are addressing at this conference. I would like to share these with you.

Of the 2,135,000 estimated population of people with epilepsy, approximately 76% develop the condition prior to the age of 18. We are, therefore, speaking about a potentially large number of persons who could become "the aged developmentally disabled with epilepsy." People with epilepsy are not homogeneous. Some have only one of two seizures throughout a lifetime; others have frequent and recurring seizures. For nearly half of the estimated 2,135,000 Americans with epilepsy, medication controls seizures and permits them to lead nearly normal lives.

In fulfilling its mandates to survey medical and social management, investigate current and potential programs, and develop a comprehensive nationwide plan for addressing the problems created by epilepsy, the Commission gathered information from many sources, including:

1) consumer workshops;
2) regional hearings;
3) expert workshops;
4) professionally prepared position papers;
5) analyses of existing Federal and state programs;
6) literature reviews;
7) assessments of available manpower and resources; and
8) analyses of the costs and the scope of epilepsy.

The Commission for the Control of Epilepsy and Its Consequences has established an overall purpose for the plan:

> The Plan for Nationwide Action on Epilepsy has been developed to enable the people of the United States and its territories to achieve effective prevention and control of epilepsy, and to reduce the negative impact of the consequences of epilepsy both for individuals and their families and for the nation as a whole.

In addition, after documenting extensive problems in such areas as: (1) medical care; (2) employment; (3) social adjustment and mental health; (4) education; (5) insurance; and (6) financial assistance, the Commission developed two specific goals:

1) to reduce substantially the number of people who suffer from epilepsy by discovering and applying effective methods for the prevention of the various forms of epilepsy; and

2) to control seizures and to ameliorate their impact so that affected individuals may attain, as much as possible:

    a) good health;
    b) living in the least restrictive environment;
    c) satisfying work at an appropriate level of skill;
    d) financial security; and
    e) social and emotional adjustment.

As a national organization, we are concerned with the needs of persons with epilepsy. Areas that we see as particularly significant for elderly persons who are developmentally disabled with epilepsy are:

1) research;
2) medical services and national health insurance;
3) social adjustment and mental health;
4) independence and equality;
5) living arrangements;
6) education for the individual, the family, the public and the professional; and
7) a comprehensive epilepsy service network that includes a a focus on the aged person with epilepsy.

Let me take a few minutes to expand on some of these.

## Research

Despite recent advances, much remains to be learned about the causes and the mechanisms of seizures. We need to achieve greater understanding of the causes of epilepsy and to develop improved techniques for prevention, diagnosis, treatment, and control through research to provide precise data on the incidence, prevalence, and prognosis in the population of elderly people with epilepsy; greater effectiveness of service delivery programs for those with epilepsy; precise information on the spectrum of problems of aged persons with epilepsy, how many such people there are in need of services, and what those service needs are.

## Medical Services and Health Insurance

A tremendous disparity exists between what is possible and what is being done for those with epilepsy. The needs for following certain minimum standards of medical care, for prompt and informed emergency treatment, and for assuring quality control are particularly apparent. We need to assure adequate standards of care for treatment of elderly developmentally disabled persons with epilepsy so that the possibility of seizure control is maximized. We need to assure that this population will receive adequate medical services by establishing minimum standards of care for diagnosis and treatment. We need to assure quality control of laboratory facilities. The provision of prompt and knowledgeable emergency care is urgent. We must coordinate existing resources to assure adequate health care.

National Health Insurance

It is often difficult for a person with epilepsy to obtain health insurance of any kind. In a survey conducted by the Commission it was found that 40% of all people with epilepsy had problems obtaining medical/hospital insurance, and 37% had difficulties obtaining accident insurance. This is also true of the population we are discussing today.

The Epilepsy Foundation of America recommends that the costs of drug treatment over an extended period of time be included as a national health insurance benefit. Persons with epilepsy often require lifelong drug treatment in order to hold jobs or function effectively in society. The cost of medication places a heavy financial burden on those people.

We urge you, in your consideration of national health insurance, not to confine your thinking to coverage of surgical and drug treatments of medical conditions. There is increasing and substantial evidence that new forms of treatment such as biofeedback are useful in controlling or ameliorating medical problems. Consumers should be provided the opportunity to have access to these new forms of treatment without financial penalty.

A person with epilepsy who does not have perfect seizure control is unable to obtain a driver's license. The Epilepsy Foundation of America suggests that assistance with costs of transportation to medical facilities be provided when a person who is eligible for health services is financially unable to meet such transportation costs and when public transportation is unavailable.

If the administration proposes that persons who are covered be responsible for paying a portion of their insurance costs, special consideration must be given to the impact of this requirement on those who are in reduced financial circumstances. The cost of health insurance premiums should be one of the criteria to be considered when eligibility for public assistance is determined and when benefit levels are established.

If it is decided that the Federal government's role should be limited to the organization, not the administration, of a national health care delivery system, it is essential that minimum standards be established to govern the quality of services provided. It is equally necessary that uniform financial guidelines be determined by the Federal government, and that the program be administered by state and local governments according to these federal standards. This would help to ensure uniformity of services among the states.

The Epilepsy Foundation of America believes that consumer participation in the implementation of a national health insurance plan is vital. This could be accomplished by mandating the inclusion of consumer representatives including the aged on the panels of any governing bodies with sign-off responsibilities for the implementation of a program of national health insurance.

Finally, if the national health insurance is to be phased in over a period of time, we would like to see the first priority given to those persons whose personal or work-related insurance program does not at the present time provide adequate coverage of expenses generated by an illness or a chronic disability such as epilepsy. Coverage could be extended gradually to all population groups according to their financial circumstances.

## Social Adjustment and Mental Health

The social, psychological, and behavioral problems that frequently accompany epilepsy can be more handicapping than the actual seizures. Yet these problems often go unrecognized and little skilled assistance is available. We need to assist in the social adjustment and mental health of all aged persons with epilepsy and their families in order to optimize their total life functioning. We should ease the social adjustment and mental health problems of people with epilepsy by providing effective and informed counseling; assuring access to social and recreational programs; and coordinating and activating effective community-wide mental health systems which are prepared to meet the specific needs of this population.

## Independence and Equality

Numerous barriers impede the goals of attaining independence and equality to the maximum extent possible. Specific barriers include: (1) language and cultural differences; (2) discrepancies in existing Federal financial aid requirements; and (3) discrimination of some service areas. We need to assure the attainment, to the maximum extent possible, of independence and equality as guaranteed by law.

We should provide a substantial increase in the possibilities for independent living and equality of treatment for aged people with epilepsy through such measures as:

1) promoting the concept of self-help;
2) providing universal access to life, health, and automobile insurance coverage;
3) providing income maintenance support services coverage for those in need;
4) guaranteeing access to all public transportation facilities;
5) evaluating and correcting safety problems that create architectural barriers;
6) assuring equal access to housing, recreation, and other public services; and
7) providing an effective legal advocacy and legal service system.

Living Arrangements

Those persons severely handicapped by epilepsy have multiple needs that are not being met. For residents of large facilities, medical care for epilepsy is often not adequate; educational, vocational, and other social services are frequently not provided. Within communities, the need for a variety of supervised living facilities is apparent.

We need to provide a continuum of services and the least restrictive living environment possible for the population we are addressing today. We should assure a continuum of services and variety of living arrangements by implementing such measures as:

1) reducing by 20% the number of persons with epilepsy in large, isolated residential institutions;

2) reducing the isolation of residents of institutions by integrating them into the community for such services as education, rehabilitation, and medical care;

3) requiring minimum standards of client care and staff competency regarding the problems of the aged person with epilepsy in all facilities housing persons with epilepsy;

228

4) developing individualized treatment plans which address medical, social, and educational needs whether in the community or in a residential facility; and

5) providing a range of varied living facilities within communities as alternatives to institutionalization.

## Research

The need for greater understanding and awareness of the problems of those persons with epilepsy is apparent at all levels. Individuals and their families often do not comprehend the problems or the potential; many professionals, including physicians, have not been adequately trained; and the public still rejects and scorns those afflicted with this condition. It is important to translate into practice existing knowledge about the aged person with epilepsy. It is vital to rapidly disseminate the new knowledge that is generated by current research in order to increase awareness and understanding of the problem.

## Available Resources

The many existing resources that could be of assistance to this population are currently not responsive to their needs. No mechanism exists for coordinting services or providing the comprehensive care that is needed. We must develop a comprehensive and responsive service network accessible to all individuals with epilepsy and their families, and to be sure that the needs of elderly developmentally disabled persons with epilepsy are specifically addressed.

# AGING AUTISTIC PEOPLE AND THEIR NEEDS

Katherine S. Stokes

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It is a pleasure to be speaking for the National Society for Autistic Children (NSAC) at this conference on Developmental Disabilities and Gerontology. Preparing the address has made me realize that many professional persons are unaware, not only of the needs but of the very existence of aging autistic persons. Several parents, searching for services for their autistic young adults have been greeted with incredulity and with comments such as, "Autistic adult? But I thought it was infantile autism!" A professional to whom I mentioned the topic of this talk said with surpise, "But autistic children die young don't they?" Many professionals have not yet faced the reality that an autistic child grows up to become an adult. A NSAC parents' group, while polling an agency as part of a study on the incidence of autistic adults, was eagerly told, "We don't have any yet, but we expect some in a few years!" That is my position here today. As the syndrome of autism was identified only 35 years ago, we don't have any aged autistic people yet, but we expect some in a few years.

## History and Objectives

The National Society for Autistic Children is a young organization. Founded in 1965 by a small group of parents and children, it has grown from a handful of local and state chapters to its present 110 chapters, 12 state societies and approximately 6500 members who include parents, friends, and concerned professionals. In 1975 autism as a disability was included under the Developmental Disabilities Act. This year NSAC will hold its tenth annual conference the week of June 28 to July 1 in Dallas, Texas.

NSAC was founded in order to promote the welfare of autistic children. These are persons with a severely incapacitating and lifelong developmental disability which typically appears during the first three years of life and is manifested by: (1) severe disorders in ability to communicate with other persons; (2) abnormal ways of relating to people, objects and events; (3) abnormal responses to sensations; and (4) uneven and disturbed development of social, language and cognitive skills. These handicaps are, in many cases, accompanied by severe behavior problems. Given this cluster of disturbances, autistic people demonstrate a wide range of ability, from severe retardation to high intelligence. IQ testing indicates approximately 60% with scores below 50, 20% between 50 and 70, and only 20% with scores greater than 70.

Until very recently the thrust of NSAC's efforts has focussed on children. According to its by-laws the organization's purposes include: (1) research into prevention, care and cure of autistic children; (2) integrated care for autistic children including diagnosis, education, training and recreation; (3) the establishment of facilities to meet these needs; (4) the training and education of professionals and parents; (5) the formation of parent groups; (6) better public understanding of the problems of autistic children including active collaboration with other organizations serving DD populations; and (7) gathering and disseminating information regarding autistic children. NSAC publishes a newspaper, runs an information and referral service and engages in lobbying efforts for autistic people.

## NSAC's Current Activities and Concerns for Older Persons

NSAC's central efforts for autistic people of all ages have thus far been centered on changing public policy to include the handicap of autism. Intensive work continues at national, state and local levels to raise the consciousness of legislators and policy makers concerning the disorder. There is an ongoing effort to see that autistic children and adults are included under already existing funding mechanisms such as Vocational Rehabilitation, Title XX, and HUD.

As the national organization has grown, so has its awareness that autistic children grow up. Within the organization, specific concern for adults has been expressed in several ways. An adult programs committee, established in 1974, presented a program on the autistic adult in the community at the 1975 national convention. The theme of each succeeding convention has been concerned with the autistic citizen; this year's annual meeting should complete the process of changing the name of the organization from National Society for Autistic Children to National Society for Autistic Citizens. The Board of Directors has endorsed the concept of establishing a trusteeship plan to provide lifetime monitoring of facilities and programs for autistic persons.

## Autistic People and their Needs

Autism is indeed a life-long disability. Autistic people can be expected to live a normal life span. Their physical health is usually excellent. Typically they do not present physical disabilities commensurate with the severity of their social, language, cognitive and behavioral deficits. As far as we know the process of aging is unaffected by the disorder of autism.

The children, first identified as autistic by Kanner in 1943, are now in their late thirties or early fourties. Where are they? As Segal (1978) has pointed out, it is difficult to identify elderly DD persons in the community. It may be even more difficult to identify elderly autistic persons for the following reasons:

1) the oldest persons diagnosed as autistic are only 40 - 46 years old;

2) professional unawareness of autism in adults;

3) some autistic symptoms are less apparent in later years;

4) the range of disability among autistic populations is very wide. Some are functioning in the community in various degrees of independence or dependence; probably the greater majority of aging autistic persons have, for many years, been living in institutions for the mentally retarded and mentally ill; and

5) typically the diagnosis of autism becomes obscured or lost. Persons able to function in the community slip into the mainstream as normal if somewhat eccentric persons, or as they receive support from varied social and health agencies they are diagnosed as having the appropriate diagnostic category for that agency. Similarly those admitted to institutions serving the mentally retarded or mentally ill take on the label that is appropriate to the purposes of the institution.

Studies by Leo Kanner and Janet Brown give some indication of the outcome for autistic adults. Among 96 patients diagnosed before 1953 Kanner has identified 11 who function "as self-dependent individuals, mostly well educated and all gainfully employed" (Kanner, Rodrigues & Ashenden, 1972). A survey of 125 autistic-like persons over 21 years old conducted by Brown (1977) indicates that 21 are living independently, and 52 function at very low levels and are living in institutions or sheltered schools; most of the rest are living at home with parents or in communal living situations.

Decisions regarding needs of aging autistic persons can be made only by projecting from information just beginning to be available about autistic adults. Two papers describe the characteristics of the mildly autistic or "near normal" adult functioning in the community (Dewey & Everard, 1974; Everard, 1976).

In preparation for a forum on the autistic adult to be held at this year's NSAC convention I have been contacting parents of autistic adults in an informal needs assessment survey. Although only a few of these autistic persons could be considered "older" and none of them "aged" there are indications of needs to be met.

Before specifying these needs I must describe the present functioning of these autistic adults. Although the handicaps of autistic people exist in a continuum of disability, I have arbitrarily divided them into the severe, moderate and mildly impaired. I must stress that the syndrome of autism is, in itself, a severe disorder. It is like being a little bit pregnant; it may not show, but it's still there.

The mildly autistic person is one who has overcome enormous obstacles in order to reach his present level of adjustment and that adjustment is fragile. He can nearly manage his own affairs. He may be living independently, or more typically still lives with his parents, even at age 40. He holds a job of sorts. He has graduated from high school or rarely, college, and may be exceptionally talented in certain subjects such as music, computer programming or electronics. He is, however, unlikely to hold a job commensurate with his talent because of anxiety about the unexpected and his inability to understand the changeableness and subtleties of human relationships. He is more dependent than he realizes on parental guidance and assistance, assistance that must be discreet and disguised in order to be accepted.

For a person whose basic handicap is difficulty in communication he speaks and understands reasonably well. He is likely to have difficulty in listening to others, and he may be overtalkative and intense, without realizing the other person is not as interested as he is. Socially eccentric and unaware of the subtleties of interpersonal relationships, he often displays a naivete described by several parents as a "strange innocence." At the same time he is acutely aware that he is different, is pained by this, and does not understand why. He longs for companionship, a girl friend. He cannot understand his failure and their rejections. He has difficulty in judging the depth of a relationship. Anyone who is kind or has been helpful is a friend, and this innocence can present a danger of being used and abused, of being taken advantage of. Parents of the near normal autistic person are especially anxious about his future when they are gone. Aware of his dependence, they are concerned about how well he will cope "without the safety net of being recognized as handicapped" (Everard, 1976).

The deficits of the severely or profoundly autistic person are at the other end of the same continuum. He has very poor to no communication skills, minimal ability to form reciprocal relationships with other persons, severe retardation, and, in many cases, episodes of unpredictable and destructive behavior. In spite of these handicaps he is likely to have isolated skills of a much higher order. He may be able to recognize and spell hundreds of words for objects, picture and persons and reproduce them from memory months later, yet be unable to communicate his own needs or ideas either verbally or in writing. Another autistic person can tell upon which day of the week May 21, 1890, fell, or he can do mathematical calculations in his head such as multiplying two sets of four-digit numbers, yet he has no understanding of arithmetical priciples, nor can he solve simple problems. A 23-year-old autistic man is physically very strong, is able to handle carpentry tools, push a heavily loaded wheelbarrow across a narrow plank, transplant delicate seedlings, but cannot speak, read or write. None of the severely impaired can use their skills independently to organize and complete a task; judgment is almost totally lacking. He is unable to make use of leisure time, will revert to deep autistic withdrawal or disruptive behaviors if time and space are not structured and the environment is not intrusive. In spite of these handicaps, with long and painstaking training he can be taught self care, home maintenance and some work skills. Most of these people have received little or no appropriate education or training during their childhood years; consequently it is impossible to predict their potential level of functioning. Severely impaired autistic persons are usually not accepted even in sheltered workshops because, although their potential work skills and rates of production may be high, their disruptive behaviors and inability to understand directions and social expectations are unacceptable.

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The moderately autistic group comprises the vast range of persons between these two extremes. Such a person, although able to express needs concretely but adequately, nevertheless has speech that is labored and queer, and is not used conversationally. He can learn rule-governed behavior and rigidly follow it, enabling adjustments to routine living situations and work schedules. He may be able to perform intricate wiring, key punching and calculating as long as the work settng is tolerant of his peculiarities and his extreme anxiety about errors and the unexpected. His work history is typified either by a job below his mental capabilities which he may nevertheless lose because he cannot handle the pressure for 8 hours, or by a menial, undemanding job which he can retain, or by marginal success in a sheltered workshop. He lives at home with his parents, and needs supervision in any situation that is not routine. He may be able to get to work on his own after careful preview of the route and means of travel, but any change must be carefully rehearsed before he can resume independence. The moderately handicapped group is unlikely to be able to live independently; there is continued need for someone to fall back on.

## Recommendations

From the above it will be seen that all but the most mildly autistic person need residential situations that include varying amounts of supervision or support. The majority require specialized, sheltered and/or structured work settings. Almost all autistic persons need social support.

These areas of needs should guide future legislation as well as planning and policy making around funding mechanisms. Unfortunately, autistic adults are too often excluded as beneficiaries of existing funding. Let me be more specific about these areas of needs:

(1) There is a need for funding that is flexible and adequate enough to support varied living arrangements: (a) the severely autistic person needs totally supervised, structured programs with high staff ratio, programs that include ongoing skill training in self care, home maintenance, leisure time activities, communication skills and behavior control; (b) moderately handicapped autistic people can live in cooperation with other persons with varying degress of support. The funding focus should be on flexible use of a variety of facilities, such as supervised apartments, farms, communes, dormitories, as well as foster and group homes. In spite of normalization pressures against institutional living, communal living in a sheltered or semi-sheltered village may be the situation of choice for the moderately and severely handicapped. In addition, rural life may be a particularly felicitous environment for autistic persons as it provides many opportunities for effective and satisfying functioning.

(2) There is a need for funding that is flexible and sufficient to provide autistic people with work and work training in sheltered settings and supervised projects. The most striking gap in services is long term funding for sheltered employment for all developmentally disabled people "whose prognosis for being able to perform work in private, competitive employment is poor [to nonexistent] because of the severity of their handicap" (Uhlig, 1978). For these people the focus of federal and state dollars will be not on work rehabilitation but on long term sheltered employment and long term work training. All severe and most moderately impaired autistic persons need this extended funding.

(3) There is a need for specialized and ongoing social supports and therapies for the mildly and moderately autistic person living in the community. These should include: (a) assistance in times of crisis; (b) assistance in problem solving; (c) social skill training; (d) training and/or assistance in self control; and (e) a person or agency to act as a bridge to the outside world. Each autistic person needs a interpreter-facilitator-friend who can help him not only to find but also to use available community resources such as jobs and recreational opportunities. Both he and the community need help in understanding one another. This requires a kind of ongoing interpreter who can (a) help the autistic person understand social nuances, and (b) help the agency to tailor expectations to the autistic person's social handicap.

This person should be one with a thorough understanding of the autistic person's deficits and strengths, as well as the kinds of interventions that enable him to circumvent their crippling effects. Such a person could be a logical extension of those educational centers already working effectively with autistic chilren, or he might be a specialist on autism based in a community mental health center. What is important is that the autistic person knows where he can go to get the help he needs, that it be a single resource with multiple functions, and one that can help him deal with the many facets of his life. His is a need for ongoing mending and tending.

Without these services, without this support, the desperately hard won independence and decent self-concept are constantly threatened by his social and communication deficits and the reactions from others that they elicit. Without this support he becomes confused, more and more withdrawn, and eventually regresses to the point of institutionalization. The aging process would only exacerbate this deterioration. At present, for those who are lucky enough, these support services are being provided by the families of autistic adults. What will happen to the latter when their parents die?

(4) There is a need for respite care for families who continue to keep their autistic member at home. This is a service parents and siblings are presently shouldering for the community because there is no one else to do it.

(5) There is a need for training of persons to work with autistic people. Curriculum should include not only all behavioral technologies but also cognitive and language development and environmental management.

(6) There is a need for research into the characteristics and needs of adult and aging autistic persons and for pilot projects assessing their capacity to continue to learn more adaptive behaviors and increasingly complex social interactions into the middle and later years.

I began this talk by paraphrasing an agency which said "We don't have any aging autistic persons yet, but we expect some in a few years." That is indeed our situation and will continue to be unless a national effort is mounted to reassess our state hospital and state school residents so as to identify those persons who have been autistic all along. For those already identified, now is the time to prepare for their older years because they are coming indeed.

The needs of autistic persons are vast and mostly unmet. Autism is a relatively rare disorder; only 4 in 10,000 people. Although the rate of funding needed to meet adequately the individual's needs is high, especially for the severely autistic person, the total amounts of money are finite. This is a population of often delightfuul, strangely innocent, frequently odd but lovely persons who have been seen as the most difficult of all disabled persons to educate and habilitate. The technology to help the autistic person is beginning to be demonstrated. Good results have been shown. The older autistic person has benefited from none of this. Surely his time has come.

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# CONFERENCE EVALUATION

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The invitational consultation-conference on "Developmental Disabilities and Gerontology" registered a total of 66 participants representing administrators, direct service workers, and researchers in the fields of gerontology and developmental disabilities. Each state, plus Puerto Rico and Washington D.C. were represented. At the conclusion of the consultation-conference, each participant was asked to evaluate various aspects of the meetings. For this purpose a Feedback Form was included in the consultation-conference workbook (see Appendices). The following paragraphs describe the Feedback Form and the responses that were provided to the three-day meetings.

## The Consultation-Conference Feedback Form

The Feedback Form consisted of fifteen questions designed to elicit reactions to the following aspects of consultation-conference: 1) expectations held prior to attending the consultation-conference; 2) expectations met or not met by the consultation-conference; 3) the most and least valuable aspects of the consultation-conference; 4) benefits related to professional growth realized by attending the consultation-conference; and 5) recommendations for future consultation-conferences concerning the aged developmentally disabled.

Each participant was asked to respond in detail to the questionnaire in order that the completed forms could be utilized to measure the overall effectiveness of the consultation-conference and to provide a basis for future planning.

## Responses to the Evaluation Form

Many respondants reported that among the most valuable aspects of the conference were the personal contacts and information-sharing with other individuals in the fields of aging and/or developmental disabilities. Twenty-one participants noted this, with several of these commenting that the variety of backgrounds and experience of participants added an important dimension. Fourteen respondents felt that the well-organized format and schedule were the most valuable aspects. Nine people specifically mentioned particular workshops, but opinion was divided among them as to which one was actually the best.

Five participants stated that there was no least valuable aspect of the conference. Ten participants felt that the presentations were the least valuable part of the conference. Several people were frustrated by the Workshops. Some felt the workshop focus was too limited, while others thought the workshops attempted too much.

Participants overwhelmingly agreed that the group invited to attend the conference was well-chosen. Comments repeatedly found in the evaluations were that the participants were knowledgeable, dedicated, and represented a good cross-section of experience and expertise. A majority of the respondants stated that the conference setting was comfortable and appropriate, although some would have preferred to be in the city.

A variety of long- and short-term benefits were noted. As a result of the conference, several participants felt they would be more capable of planning and programming for the aging and aged developmentally disabled in their agencies. Others listed such benefits as increased awareness and understanding of problems of this population. Five respondents felt that the professional contacts they had made at the conference would be beneficial to them in their future job responsibilities. Others felt they had gained information that would be useful in their work.

Overall, participants felt that this conference was helpful in broadening their knowledge base and understanding of the aging and aged developmentally disabled persons. Several people felt that the conference served as an impetus for planning and for evaluating current programs. A few respondents felt that the conference clarified the need for additional data.

The latter portion of the questionnaire requested information that the conference participants felt they needed as a result of the conference. The most common response was a request for more specific demographic data regarding the aging and aged developmentally disabled. Additional information about specific programs was also requested as well as about more general programming options.

Recommendations for future meetings on aging and aged developmentally disabled persons included the idea that participants should be invited back to another conference to determine what they have accomplished and what impediments they have encountered in implementing services. Other suggestions included inviting more consumers, federal officials, therapists and educators to future conferences. Several respondents thought that requiring advance preparation was a good idea and felt this should be retained.

## Summary of the Responses

Of the 66 conference participants, 34 answered and returned the conference feedback form. Thirty-one individuals identified their role as that of "participant"; one, as that of a "consultant"; one as "participant/speaker"; and one as "participant/presenter."

Participants indicated that their expectations were more general than specific prior to the conferences. Many individuals expected opportunities to learn more about the aging and aged developmentally disabled and their problems. Others expected a great deal of mutual information-sharing and ideas for new programs. Several participants also had expectations for policy promulgation and for meeting with other professionals in the field of aging and developmental disabilities. Only two participants indicated no previous expectations.

The majority of the responding participants felt their prior expectations had been met, entirely or in part. Fourteen participants felt that they had gained useful information about the aging and aged developmentally disabled in terms of needs, programs, programmatic options, and the necessity for coordination. Others felt it was useful to have shared ideas and expertise with people from other parts of the country. In particular, many participants appreciated the opportunity to meet other professionals in the field of developmental disabilities. One person especially enjoyed the wide range of speakers; another, the experience of participating in a "working" conference.

In varying degrees, participants felt that some prior expectations were not met. While 18 respondants listed no unmet expectations, 16 respondants expressed widely varying unmet expectations.

One person felt there should have been more interaction and discussion of unique programs. Another was disappointed that no definitive action resulted from the conference. One respondant felt that the participants in the conference were not given ample opportunity to share their expertise and to use it in a working session. The respondant wondered whether the Conference was held to justify present funding or to encourage future funding.

It was apparent that the Conference filled the needs of many of the participants but also failed to meet the expectations of some. There was no question however that almost all of the participants gained something from their attendance, the primary gain for most being the opportunity to interact with their colleagues working in the fields of developmental disabilities and gerontology. The overall response to the Conference was a positive one and each of the thirty-four evaluations provided insightful comments related to the three-day meetings. The responses offered important suggestions which will form the basis for planning future meetings designed to address the service needs of the aging and aged developmentally disabled person.

# APPENDICES

APPENDIX A

## AGENDA

## A NATIONAL CONFERENCE ON GERONTOLOGY AND DEVELOPMENTAL DISABILITIES

Institute for the Study of Mental Retardation and Related Disabilities
University of Michigan
Ann Arbor, Michigan

### Monday, May 8, 1978

8:30 a.m. Registration

9:00 Introduction and Overview - Robert Segal, Ph.D.
Videotape, "The Aging/Aged Developmentally Disabled Person"

10:00 Coffee

10:15 Workshop I - THE AGING AND AGED DEVELOPMENTALLY DISABLED PERSON: DEFINITION AND CLARIFICATION

12:00 p.m. Luncheon (Marriott Inn)

1:15 FIVE AGING/AGED DEVELOPMENTAL DISABILITIES PROJECTS AND IMPLICATIONS FOR PROGRAM DEVELOPMENT

Moderator: Doris Haar, Developmental Disabilities Office, HEW

Presenters: S. Hartig, Georgia
N. Thomas, Michigan
W. Hitzing, Nebraska
C. Hanf, Oregon
A. Hofmeister, Utah

3:15 Coffee

3:30 Workshop II - IDENTIFICATION AND PRIORITIZING OF PROGRAM, POLICY, AND SERVICE NEEDS

4:30 Reports of Workshops I & II to General Assembly

5:15 Adjourn

### Tuesday, May 9, 1978

9:00 a.m. Overview

9:15 A SERVICE NEEDS ASSESSMENT OF THE ADULT AND OLDER DEVELOPMENTALLY DISABLED PERSON AND ITS IMPLICATIONS FOR SERVICE DELIVERY

Moderator: Nola Thomas, M.S.W., A.C.S.W.

Presenter: John Gordon, Ph.D., Director
Neuro-Psychology Laboratory
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10:15 Coffee

10:30 Workshop III - RECOGNITION AND RESOLUTION OF IMPEDIMENTS TO SERVICE DEVELOPMENT

12:00 p.m. Luncheon (open)

1:30 Workshop IV - NEW DESIGNS AND GUIDELINES FOR SERVICES

3:00 Coffee

3:30 Workshop IV (continuation)

5:00 Adjourn

## Wednesday, May 10, 1978

9:00 a.m. ISSUES CONCERNING THE DELIVERY OF SERVICES FOR THE AGING/AGED DEVELOPMENTALLY DISABLED FROM A NATIONAL PERSPECTIVE

Moderator: Leo Voytko, ACTION Programs, Washington, D.C.

### From the Government Perspective

Doris Haar, Developmental Disabilities Office, HEW
A.D. Buchmueller, President, Committee on Mental Retardation, HEW

### From the Consumer Perspective

John Pezzoli, National Association for Retarded Citizens
Carol Murphy, United Cerebral Palsy Association
Hal Benson, National Association on Epilepsy
Katharine S. Stokes, National Association on Autism

12:00 p.m. Luncheon (Marriott Inn)

1:00 Reports of Workshops III & IV

1:45 Closing Remarks and Future Directions - Robert Segal, Ph.D.

2:00 Adjourn

# APPENDIX B

## CONFERENCE PARTICIPANTS

National Conference on Developmental Disabilities and Gerontology
May 8-10, 1978
Ann Arbor, Michigan

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# APPENDIX C

# EVALUATION FORMS

## CONFERENCE EVALUATION FORM

Date ____________________

1. Overall conference was:

   ____ Excellent ____ Fair

   ____ Good ____ Poor

2. Material presented:

   ____ Offered new substantive information

   ____ Inhibited learning by:

      ____ Not having enough discussion

      ____ Attempting to cover too much matrial

      ____ Other ________________________________

COMMENTS:

## CONFERENCE FEEDBACK FORM

We would appreciate your feedback to assist us in evaluating the Consultation-Conference on Developmental Disabilities and Gerontology and to aid us in planning future activities. Your particular perceptions will be useful to us in this endeavor. The results will be included in the evaluation report which you will receive.

Thank you.

In this conference, my role was that of ________________________ (i.e., participant, consultant, speaker, etc.).

1. My original expectations for this conference were __________________
____________________________________________________________________
____________________________________________________________________

2. My expectations have been met in that ____________________________
____________________________________________________________________
____________________________________________________________________

3. My expectations have not been met because _________________________
____________________________________________________________________
____________________________________________________________________

4. The best things about the conference were _________________________
____________________________________________________________________
____________________________________________________________________

5. The worst things about the conference were ________________________
____________________________________________________________________
____________________________________________________________________

6. If I had my way, I would change the conference by _________________
____________________________________________________________________
____________________________________________________________________

7. The participants in this conference ______________________________

________________________________________________________________

________________________________________________________________

8. More conferences of this type should be offered to ______________

________________________________________________________________

________________________________________________________________

9. The physical setting of the conference can be evaluated as ________

________________________________________________________________

________________________________________________________________

10. The conference should be followed up by __________________________

________________________________________________________________

________________________________________________________________

11. The short-time benefits of the conference in my professional work were ____________________________________________________________

________________________________________________________________

12. The long-term benefits of the conference in my professional work will be ______________________________________________________________

________________________________________________________________

13. The information given at the conference was helpful in ___________

________________________________________________________________

________________________________________________________________

14. The additional information about the aging/aged developmentally disabled not provided by the conference that I need now is _____________

________________________________________________________________

________________________________________________________________

15. If the Institute should consider offering another conference such as this one, I would recommend ___________________________________

________________________________________________________________